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ABSTRACT

Provided is a collection of 23 papers on current services for deaf-blind individuals with four sections on background information, medical and diagnostic perspectives, home visitation and parent counseling, and other topics which include research, program evaluation, and legislative and legal action. Among the entries included are the following titles and authors: "A History of Centers and Services for Deaf-Blind Children" (R. Dantona); "Primary and Secondary Prevention of Deaf-Blindness" (P. Ziring and L. Cooper); "The Ophthalmologist and Educator--Their Interactions in the Care of the Deaf-Blind Child" (A. Murphree); "Case Finding and Referral" (P. Mershon); "Infant Stimulation Programing for the Deaf-Blind" (M. Appell); "Vocational Rehabilitation for Deaf-Blind Youth and Adults" (L. Bettica); "Training of Personnel" (V. Hart: "Research Needs in the Area of the Deaf-Blind" (W. Blea and D. Overbeck); "Touch Communication" (R. Kinney); and "The Current Status of Information and Service Resources for Deaf-Blind Persons in the United States in 1975" (L. Alonso). Also provided are a list of annual directories, a directory of resources, and tables on the regional centers serving deaf-blind children, the federal network of media services, the resource centers network, and public health, educational, information, and financial assistance resources. (SBH)

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STATE OF THE ART

Perspectives on Serving Deaf-Blind Children

Edited by

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and

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for

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Acknowledgment

This document is a testimony not only to the dedication and expertise of those people who care for and educate deaf-blind children, but to the continuing effort and commitment on the part of our state, local, and national governments to provide services to the severely handicapped deaf-blind child.

When, in 1963, a rubella epidemic left us with more than 5,000 deaf-blind children scattered across our country, there was no way to assure appropriate services to these children.

Recognizing this as a national emergency, Congress responded by allocating the funds needed to provide services and programs for these children. Through their efforts, concern, and foresight, these children are being served. The Executive Branch, under four presidents, has added its support.

We feel *State of the Art* is a significant document; a milestone marking the achievement possible when the nation as a whole recognizes its responsibilities and expresses its concern for each citizen by seeking to fulfill these responsibilities through a united, concerted effort.

Not all needs of the deaf-blind have been met nor have all the answers been found, but the information recorded within these pages is significant for all of us involved with deaf-blind children and justifies our hope for these children in the future.

We know that deaf-blind persons will need specialized services throughout their lives and that a continuing national effort will be required to meet these needs. This document testifies to the efficacy of that commitment and to our ability to meet these needs. As our nation serves the deaf-blind, we express our belief in the importance of each and every citizen.

EDWIN W. MARTIN
*Deputy Commissioner
Bureau of Education
for the Handicapped
U.S. Office of Education*

Foreword

The program of centers and services for deaf-blind children is no longer in its infancy. The program has been active for a period of almost seven years now, and the time has come to consolidate the knowledge developed during that time into one package for quick and constant reference.

Initially, this document was intended to represent the state of the art in serving the deaf-blind, but it does not. Some areas of service are not represented; some persons contributing would have been better chosen to represent other aspects within the field; and some persons who are not represented would have much to contribute. In addition, two years have elapsed since the project was first initiated. This time lapse represents changes within the field, especially in the areas of prevocational, vocational, and alternative living skills for the deaf-blind.

The state of the art has grown and moved beyond us—which is as it should be. But that in no way lessens or negates the efforts or the contributions of the people who prepared papers for this document nor those of the field as a whole. The fact that all problems have not yet been solved—or perhaps even anticipated—does not diminish the very real contribution provided by the authors of the papers contained within.

All of those entering the field of service to the deaf-blind must have available to them a document which includes the most complete statement of services available. We trust that this document will stimulate them and encourage them to make their own individual and unique offering to the solution of the problems that face us. Our ultimate goal is to provide the knowledge and the service needed to give each and every deaf-blind individual the opportunity to develop to the fullest potential of which he or she is capable.

With hindsight and the passing of time one can easily say “yes, but it didn’t . . .” or “you could have” One can wait forever for the perfect time or the perfect moment, but the children we serve cannot afford to wait any longer. We owe them the best we can offer right now and the hope that what tomorrow offers will be even better.

ROBERT DANTONA
*National Coordinator, Centers
and Services for Deaf-Blind
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for the Handicapped, U.S.
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Preface

One of the functions of leadership is to provide direction and guidance. Because the deaf-blind population is so widely dispersed and because services are growing as rapidly as they are, this direction and guidance is almost impossible to provide on a personal basis.

One of the hallmarks of an established field is a formalized communication pattern which allows for the dissemination of information over a wide geographical area and across many professional boundaries. However, among those serving the deaf-blind, communication is still on an informal, almost personal basis that is no longer adequate. For the many people entering the field of service for the deaf-blind, the lack of readily obtainable information has led to feelings of confusion, anger, and frustration.

This comprehensive document was designed to provide one solution to the problem. This document can be used as a text in teacher-training courses, read by practicing teachers within their classrooms, read by parents within their homes, and used by professionals in other fields who have occasion to work with deaf-blind children. We trust that this document will provide the guidance, contact, and communication needed and the assurance that a developing body of knowledge is being applied to the services provided for deaf-blind children. By providing this guidance and assurance, this document will alleviate some of the feelings of frustration that we all have in serving the deaf-blind.

The authors of this document are all professionals within the field, heavily committed to their own projects and their own goals. To all these people I would like to say thank you. Your contribution is immense and immeasurable. I am sure that all who use this document will benefit as will the deaf-blind children we serve.

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*Deputy Superintendent
for Programs*

WILLIAM A. BLEA
*Project Director, Southwestern
Region Deaf-Blind Center*

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Introduction

Edgar L. Lowell

Director, John Tracy Clinic

The purpose of this document is to present in one convenient source a collection of papers in which are described what is being done with and for deaf-blind individuals at the present time. Since the rubella epidemic of 1964-65, the number of services for the deaf-blind has grown more rapidly than the channels of communication between them. As a result, information on the deaf-blind has been published in a variety of sources, but no single source book is readily available to those concerned with serving the deaf-blind. This document is designed to partially relieve that problem by bringing together a compendium of papers representing the state of the art in dealing with the deaf-blind at this time.

Readers are reminded that this is not a "how-to" document but rather a description of what is. We did not intend to delineate how things should be done but rather to survey what is being done in different programs in a wide variety of areas. We made a conscientious effort to cover alternative points of view when they exist, and we firmly discouraged contributors from merely presenting a description of their own program, although that element did creep into many presentations.

Contributors were selected on the basis of their knowledge about specific program areas. Some individuals had expertise in so many areas that deciding which subject to ask them to cover was difficult. Other areas included so many qualified persons that it was difficult to choose one. For a few areas, we had difficulty in finding anyone qualified to contribute a paper. The coverage is uneven, and some areas have been largely neglected. Perhaps that is an accurate representation of the state of the art in the field of the deaf-blind today.

The careful reader will note that we have not forced on the contributors a rigid definition of the term "deaf-blind." For some, the definition did not appear to be important; others have provided the definition they were using. In general, we assumed a working definition of "one whose vision and hearing is so impaired as to seriously interfere with participation in an educational program designed for either the deaf or the blind." This working definition avoids tying the hearing or vision loss to any measurable references. Measurement is difficult and the great harm would be to exclude a person from any kind of service program because of a failure to meet some measurable criteria in terms of visual acuity or hearing loss only to find later that the measurements were in error. Also, some individuals who are not severely handicapped by both their vision and their hearing—but who do suffer from additional handicapping conditions—might be suitable candidates for a deaf-blind service program.

We are dealing with a multihandicapped population. Very few of the deaf-blind in America are suffering from clear-cut deafness or blindness alone, and delays in providing appropriate service undoubtedly compound the initial disability.

This publication is organized into four sections. The first, a background section, presents a history of services to the deaf-blind in this country and a survey of overseas programs for the deaf-blind in Europe and Great Britain.

Edward Waterhouse, one of the deans of deaf-blind education, traces the history of services to the deaf-blind in this country from 1837 to 1967, leaning heavily on events that have taken place at Perkins Institute for the Blind, of which he is

director emeritus. This is appropriate in that much of the history of the deaf-blind in America is the history of Perkins. The chapter provides interesting details on the progress of Laura Bridgman and other deaf-blind students, including an account of Dr. Howe, the first director of Perkins, who wore a fencing mask and gloves to keep a particularly disturbed child from scratching his face while he was teaching her. Helen Keller and Anne Sullivan occupy an understandably important segment of the chapter. Waterhouse also traces the growth of professional organizations and the development of teacher-training activities, describing events leading up to the Anne Sullivan Centennial in 1966, which proved to be a springboard for much of the subsequent federal legislation for the deaf-blind.

Robert Dantona presents an account of the implementation of Title VI-C of the Elementary and Secondary Education Act and the development of regional deaf-blind centers. To appreciate what has been accomplished, one must remember how limited our manpower resources were at the time of the rubella epidemic. This has been a remarkable service—organizing new programs, expanding existing ones, mobilizing specialists from a variety of disciplines, and operating through a series of regional centers whose responsibility, but not necessarily authority, cut across existing jurisdictional boundaries. As might be expected of any crash program, this one has had problems. But the miracle is that it has worked as well as it has.

Jeanne Kenmore provides an overview of programs for deaf-blind children in continental Europe and Great Britain. Her tabulation of some 350 deaf-blind children enrolled in 13 countries shows great differences in the ratio of the number of children served to the general population of each country. Russia has 247 million people but reports only 51 children in special schools, while Great Britain has 56 million people and reports 101 children in special schools. Kenmore also provides a detailed account of the deaf-blind program at Saint Michielsgestel and traces its influence in Europe.

The second section contains medical and diagnostic papers that include descriptions of prevention, audiology, ophthalmology, the medical diagnostic team, and educational evaluation.

Philip R. Ziring, M.D., and Louis Z. Cooper, M.D., discuss congenital infections, genetic disorders, and postnatally acquired causes of vision and hearing problems and review incidences, clinical characteristics, treatment, and primary and secondary preventive measures.

Charles Tait describes the role of the audiologist on an interdisciplinary evaluation team. He discusses the evaluation of hearing and the different types of hearing tests that can be used with deaf-blind individuals. He points out some of the difficulties involved in audiologic assessment, including the fact that "few audiologists receive adequate training to permit them to participate meaningfully in the differential diagnosis of hearing impairment in a multihandicapped child." This may explain why the assessment of so many deaf-blind children is still incomplete or uncertain.

A. Linn Murphree, M.D., relates the interaction of the ophthalmologist and educator in the care of the deaf-blind child. He describes the anatomy and physiology of the visual system and the role of the ophthalmologist in caring for the deaf-blind child. The section on communication between ophthalmologist and educator contains suggested forms for providing and requesting information. Still another section describes low-vision aids and a particularly useful list of abbreviations commonly used by ophthalmologists.

Clinical evaluation of the deaf-blind child is described by Ellidee Thomas, M.D., as a multidisciplinary process, including such components as family-social evaluation, medical evaluation, educational-developmental evaluation, staffing, interpretation, and follow-up, as well as the use of team members as classroom resource personnel. Dr. Thomas' paper also includes an interesting and comprehensive report on a child being served at the Oklahoma Center.

In her paper on Educational Assessment, Nan Robbins describes the present status of theoretical constructs, tools, techniques, and interpretive knowledge relating to the appraisal of an individual's assets and liabilities for the purpose of "mental and moral development to be achieved through instruction from another person." Robbins' section contains a wealth of information on various standardized tests that have been used with the deaf-blind, as well as a wide variety of developmental schedules and scales that have been used to assess communication development, temperament, effect, and adjustment. She also provides a comprehensive bibliography which gives some indication of the activity in the assessment area.

The third section contains papers describing the continuum of available services: infant stimulation, parent counseling, school programs, prevocational programs, social and recreational activities, alternative living programs, and the training of personnel.

Patricia Mershon, in her paper on Case-Finding and Referral, describes case-finding techniques that are being employed in the different regions and factors which are found to influence the outcome of case referral.

The rationale for an early infant stimulation program is discussed by Madeline Appel, who summarizes relevant developmental literature and describes the components of an early intervention program.

In the section on Home Visitation and Parent Counseling, June Horsley describes the role of the home counselor and the skills that should be developed, including understanding family structure, role and dynamics, developing interviewing skills, and conducting the actual home visit.

Katherine Best describes the different patterns of schooling as they currently exist. She delineates the advantages and disadvantages of different types of programs by contrasting their objectives, facilities, population, methods and materials, and staffing, covering both residential and day programs that are state supported and privately funded. Best also deals with administrative concerns in operating a deaf-blind educational program.

Edwin Hammer's paper on Prevocational Services focuses on the preparation of the deaf-blind child for entrance into a variety of adult services. He describes a number of projects that were undertaken as part of a "cooperative study to assess the delivery and the potential for delivery of prevocational services throughout the nation."

Louis J. Bettica provides a background on rehabilitation efforts with the deaf-blind, particularly at the Industrial Home for the Blind at Brooklyn and the Anne Sullivan Macy Service. The program of the National Center for Deaf-blind Youth and Adults is described, together with examples of activities of a placement counselor.

John A. Nesbitt and Gordon K. Howard present a section on Professional Recreation Services and Programs reflecting the judgments, concerns, and positions of professionals in rehabilitation and recreation service to the deaf-blind. They point out that no more than one-fifth of the nation's ill and handicapped are receiving any type of professional recreation and leisure service. For those deaf-blind with little or no employment, this enforced leisure time is particularly difficult. The challenge for Nesbitt and Howard is "to make enforced leisure into an experience in which the individual may achieve his or her maximum potential."

Benjamin Smith describes models for the care of deaf-blind children, discussing possible alternative

living programs as the current deaf-blind population grows to adulthood. As they grow older, they will move out of the jurisdiction of the Regional Center Programs for Deaf-Blind Children and become the concern of vocational rehabilitation and particularly the National Center for Deaf-Blind Youths and Adults. The programs are funded by various federal agencies, and Smith points out the need for coordination between the programs to continue the team effort that has been developed through the regional center program and to provide a continuum of services.

Training of personnel to work with the deaf-blind is discussed by Verna Hart, who traces the development of training programs and describes the various types that are in operation at this time. She also discusses staffing models, skills, and attitudes that are needed by personnel entering the field of service to the deaf-blind.

The final section covers a variety of topics, including a report by a parent of a deaf-blind child and papers on research, program evaluation, legislative and legal action, methods of communication, and information resources.

Marjorie Becker relates a moving account of her difficulties in obtaining educational services for her deaf-blind child. While her experiences are not typical of all parents, there is probably no typical parent of a deaf-blind child. Her story illustrates vividly the problems and frustrations a parent can encounter.

William Blea and Dan Overbeck discuss research needs in the area of the deaf-blind. This field, in which personnel are heavily committed to providing service, has not been the target of a great deal of research. Blea and Overbeck address themselves to some of the needs and problems encountered and suggest a range of general research topics that have direct service applicability.

In their paper on Program Evaluation, David Tweedie and Doin Hicks point out that "evaluation becomes desirable when you think you are doing well but feel unappreciated, when you are in serious trouble, or when someone with authority over you insists that you be evaluated." Tweedie and Hicks describe five different models that are commonly used in the evaluation of general education and then turn to evaluation in special education. In the evaluation of services and programs within the field of the deaf-blind, the greater emphasis appears to be on the use of measuring or evaluation tools rather than on the development of evaluation models. The paper includes examples of a number of scales currently in use.

Frank Laski, in his section on Legislation and Legal Action, points out that "legal action by and on behalf of handicapped persons in the 1970s is drastically changing our relationship with these citizens." Laski outlines and projects major trends in legal action with an emphasis on those legal developments which have the greatest potential for impact on the deaf-blind population. He stresses the "potential of existing laws in developing legal institutions to protect and provide for deaf-blind persons in the years ahead."

Richard Kinney, president of the Hadley School for the Blind, describes methods of communication employed by deaf-blind persons. This was excerpted from another of his works, *Independent Living Without Sight and Hearing*. He describes communication methods that are commonly employed, including the alphabet glove, spelling letters into the palm, one- and two-handed alphabet, and the Morse Code.

In Information and Service Resources for Deaf-Blind Persons, Lou Alonso brings together the major sources of information and reports on current services which have the potential for being useful to deaf-blind persons. She describes the present public and private information resources and services of each resource and offers some observations on existing and unmet needs. This chapter should be a valuable reference for anyone seeking programs and services for the deaf-blind.

Inevitably, in an undertaking of this nature some topics would be overlooked. A number of topics were considered but are not included because of the difficulty of obtaining suitable material. One such topic was sex. We asked Carl Davis, who was a member of an American Foundation for the Blind-SIECUS task force on sex education for the blind, to explore the possibility of writing on the topic. While we were interested in all aspects of sex, we thought it reasonable to start with sex education. Davis mailed a questionnaire to 205 agencies responsible for the education of deaf-blind

children in the United States. Responses were received from 128 of these agencies. Only 10 reported having sex education programs, and three of these were for preschool-aged children. With such a small number of programs and the almost complete lack of literature on other aspects of sex and the deaf-blind, we decided that a suitable article would not be possible.

With the large number of deaf-blind children from the 1964-65 rubella epidemic approaching puberty, little is being done. Particularly surprising were the responses from those agencies that returned the questionnaire but that did not have a current program of sex education. Seventy-one percent said that they would like to present a program of sex education, 100 percent believed there would not be parental objection to such a program, and only 7 percent said that such a program would stimulate inappropriate behavior; however, 77 percent said that the communication skills of the students were inadequate for a sex education program, and 31 percent said that sex education would confuse students.

The topics and contributors were selected by an advisory committee consisting of Robert Dantona, Coordinator, Centers and Services for Deaf-Blind Children; William Blea, Project Director, Southwest Region Deaf-Blind Center; and Edgar L. Lowell, Director, John Tracy Clinic.

The papers were reviewed by other contributors in a series of face-to-face meetings. In this process, we are grateful for the assistance of Doin Hicks, Dean of Precollege Programs at Gallaudet College, Washington, D.C.; S. C. Ashcroft, Director of National Center on Educational Media and Materials for the Handicapped at Columbus, Ohio; and Joseph J. Parnicky, Director of Nisonger Center at Ohio State University, Columbus, Ohio, for their very considerable contribution to the review process. We are also grateful to Fern Root Roberts and Robert Frisina for reviewing some of the papers.

Education of the Deaf-Blind in the United States of America 1837-1967

Edward J. Waterhouse
Director, Perkins School for the Blind

From the earliest days of recorded history to the eighteenth century virtually no record exists of persons who were both deaf and blind. Possibly the sole exception is found in Governor Winthrop's Journal for 1637.

There was an old woman in Ipswich who came out of England, blind and deaf, yet her son could make her understand anything, and know any man's name by her sense of feeling. He would write upon her hands some letters of the name, and by other such means would inform her (Perkins, 1841).

Dugald Stewart, the nineteenth century Scottish philosopher, suggests that the great majority of blind deaf-mutes have been destroyed by the neglect or violence of their relatives (Stewart, 1812). This gloomy supposition is reinforced by conditions which have prevailed to this day in many areas of the world, particularly in Asia and Africa, where almost no information about the deaf-blind is available. Workers there among the handicapped concede the possibility that children born deaf-blind do not survive infancy. This does not explain why there are no records of those persons who had a normal childhood but became deaf-blind in adulthood. Surely these persons existed at all times and in all countries.

In the eighteenth century a few writers speculated that the deaf-blind, should such persons ever exist, might be educated. The Abbé Sicard at the Institution for the Deaf in Paris contemplated that the deaf-blind person might exist "as a possible and not altogether improbable event among the various physical calamities to which our species is liable" (Stewart, 1812).

God forbid that a child should ever be brought into the world without any substitute but the hand for the eye and ear! But as, unfortunately, such a deviation of

nature from her usual course is an event but too possible, let us consider beforehand what may be done, by way of remedy or of alleviation. To restore a man to society, to his family, and to himself, would be an enjoyment too exquisite, and a conquest too proud, to permit us to abandon the undertaking in despair (Stewart, 1812).

Early Education of Deaf-Blind Persons

Just who the first deaf-blind child was to be given an education is uncertain. Probably the first deaf-blind pupil to be taught language effectively was Victorine Morriseau (1789-1832) in Paris. She lost her hearing "at a tender age" and became blind from cataracts when she was twelve years of age. Burnet (1835) relates that she was instructed in the truths of religion "by expedients similar to those which enabled the blind to read and write." Her instruction seems to have been confined to religion, and she remained in the Paris institution until her death, happy in the thought "of the promised life to come."

James Mitchell was born on November 11, 1795, in County Moray, Scotland, the son of a minister. Mitchell's blindness, which was not absolute, resulted from congenital cataracts. His deafness was complete and also congenital. He was brought up in a cultured family and, with the help of a sister, learned to communicate by signs. Two operations on his eyes and needling of his ears failed to produce permanent results. He seems to have had at least normal intelligence and to have led a contented life with his family as a child and youth. Nothing seems to be known about his adult life or when and how he died.

Early in the nineteenth century, several deaf-blind children appeared in the United States, and

the theories propounded elsewhere had to be put into practice. Burnet (1835) was not very optimistic about the possibilities for success, not because he doubted the ability of the pupil to learn, but he questioned the endurance of anyone who attempted the task of teaching the deaf-blind.

For ourselves, though we think the education of a deaf, dumb, and blind person, even if so from birth, within the bounds of possibility; yet we also think it more than doubtful, whether any philanthropist will ever be found, who will devote himself to such a work with the disinterested zeal and patient perseverance necessary to success.

Subsequently, Samuel Gridley Howe, the first Director of Perkins School for the Blind, proved Burnet to be mistaken, an example since followed by a remarkable series of men and women, many of them Americans.

Laura Bridgman, 1829–1876

In contrast to the scanty records made of earlier deaf-blind persons, the story of the education of Laura Bridgman has been related in great detail. Dr. Howe, the Director of Perkins, kept careful records of his teaching methods and Laura's progress. The annual reports of Perkins School for the Blind contained lengthy accounts of her achievements. G. Stanley Hall (1904) ranked them among the most valuable pedagogic literature.

Some of the teachers who assisted Dr. Howe in Laura's education also kept records. Mary Swift Lamson, Laura's teacher from 1841 to 1844, published *Life and Education of Laura Dewey Bridgman* in 1879, three years after Laura's death. In 1903, two of Dr. Howe's daughters, Maude Howe and Florence Howe Hall, published *Laura Bridgman—Dr. Howe's Famous Pupil and What He Taught Her*. Laura also kept a journal for many years. She was a voluminous writer of letters, using the square-hand penmanship developed at Perkins by Dr. Howe. She is one of the most completely documented pupils of all time.

Laura was born on December 21, 1829; near Hanover, New Hampshire, the third daughter of a successful farmer and his wife. Dr. Howe describes the child as follows:

She was born of intelligent and respectable parents in Hanover, New Hampshire. When she attained her second year, she was more intelligent and sprightly than common children; she could already prattle some words, and had mastered the difference between A and B. But she sickened and came near unto death; the disease seemed to have fastened upon the external organs of sense, and in five weeks it was perceived that her sight

and hearing were forever destroyed. During seven weeks of pain and fever, she tasted not a morsel of food; for five months she was obliged to be kept in a darkened room; it was a year before she could sit up all day. She was now four years old, and her health and strength began to be established. She learned to go about the house and manifested a desire to be employed. But she was not only deaf, and dumb, and blind, her isolation was still more complete—the sense of smell was so blunted as to be entirely useless, and only affected by pungent odours; of course, half the pleasure of taste was gone, and she manifested indifference about the flavor of food (Perkins, 1848).

Laura's parents were fully occupied with the farm and household chores. They had little time to give special attention to a handicapped child. Fortunately for Laura, a friendly neighbor named Asa Tenney became her devoted friend and playmate. As soon as she could walk again, Asa would lead her out into the woods and fields, where she learned the feel of many objects and the difference between land and water. He taught her to recognize many objects, and his affection must have helped her through many difficult days. However, he failed to realize her need for a systematic means of communication, and when the time came, he could see no reason why she should leave home for school.

Fortunately for Laura, her home was only seven miles from Dartmouth College. When she was seven years old, a college student who came to the farm was so moved by her condition that he reported it to Dr. Mussey, the Head of the Medical Department at Dartmouth. Dr. Howe wrote later:

The first knowledge I had of Laura's existence was from reading an account of her case written by Dr. Mussey, then resident at Hanover. It struck me at once that here was an opportunity for assisting an unfortunate child, and moreover, of deciding the question so often asked, whether a blind-mute could be taught to use an arbitrary language (Howe and Hall, 1904).

In the spring of 1837, Dr. Howe traveled to Dartmouth and visited Laura and her parents. He eagerly offered to see what could be done to educate her. In October, 1837, Laura's parents took her to Boston, where Dr. Howe assumed personal responsibility for her instruction.

Dr. Howe allowed Laura some days to become adjusted before he started to give her actual instructions.

The first experiments were made by pasting upon several common articles, such as keys, spoons, knives, and the like, little paper labels on which the name of the article had been printed in raised letters. The child sat down

with her teachers and was easily led to feel these labels, and examine them curiously. So keen was the sense of touch in her tiny fingers that she immediately perceived that the crooked lines in the word 'key' differed as much in form from the crooked lines in the word 'spoon' as one article differed from the other.

Next, similar labels, on detached pieces of paper, were put into her hands, and she now observed that the raised letters on these labels resembled those pasted upon the articles. She showed her perception of this resemblance by placing the label with the word 'key' upon the key, and the label 'spoon' upon the spoon. A gentle pat of approval upon her head was reward enough; and she showed a desire to continue the exercise, though utterly unconscious of its purpose.

The same process was then repeated with a variety of articles in common use, and she learned to match the label attached to each one by a similar label selected from several on the table (Howe and Hall, 1904).

Up to this point, although Laura was learning more and more, Howe did not think that anything encouraging had happened—not much more success than in teaching a very intelligent dog a variety of tricks. But they were approaching the moment when the thought would flash upon her that all of these activities were efforts to establish a means of communication between her thoughts and those of her teachers.

The poor child had sat in mute amazement and patiently imitated everything her teacher did; but now the truth began to flash upon her, her intellect began to work, she perceived that here was a way by which she could herself make up a sign of anything that was in her own mind, and at once her countenance lighted up with a human expression; it was no longer a dog or parrot—it was an immortal spirit, eagerly seizing upon a new link of union with other spirits! I could almost fix upon the moment when this truth dawned upon her mind, and spread its light to her countenance; I saw that the great obstacle was overcome, and that henceforward nothing but patient and persevering, plain and straightforward efforts were to be used (Howe and Hall, 1904).

Dr. Howe now realized that if Laura continued to reach out for knowledge and understanding, she could become a well-informed and well-educated woman. This indeed happened. Her writing, including a number of poems, testified to this fact. She developed a strong religious sense. She was capable of discussing doctrinal points with a mature understanding. The question as to whether a person deprived of sight and hearing in infancy could indeed become an educated adult had been answered affirmatively and unmistakably. Her accomplishments were certainly comparable to those of many successful deaf men and women.

In 1851, Laura's schooling was considered to be complete. She was returned to her home in Dartmouth. Although she had taught the manual alphabet to her mother so they could communicate, and her family seemed to welcome her home, Laura did not adjust to leaving Perkins. She pined for the institution home and friends in Boston until her life seemed to be imperiled. She was readmitted to Perkins. A second attempt to return her to Hanover two years later also failed. From then on the fact that she would remain at Perkins all her life was accepted. She spent her days at the school, sometimes assisting with the girls' lessons, particularly sewing and handiwork at which she was highly proficient.

Whether or not Dr. Howe and the Perkins staff could have prepared her better for life outside the institution is doubtful. Clearly, Perkins protected her from experiences and pressures that might have done much harm to her sensitive nature. The day of the independent, self-supporting, deaf-blind man and woman had not yet come.

Significantly, Laura's successful education was brought about by the devotion and intelligence of untrained people. Dr. Howe was a physician, not an educator. The records do not indicate whether the succession of ladies, including Misses Drew, Rogers, Swift (Lamson), Wight, and Paddock, had any special expertise in teaching. Women at that time had no opportunity to obtain an advanced education, and none of them had access to literature which they could study on the subject of the deaf-blind, for none existed. They were, of course, fortunate in dealing with a pupil of intelligence, great eagerness to learn, and dogged perseverance.

Although Dr. Howe was a great proponent of oral education for the deaf, he did not attempt to teach Laura to speak, though he was confident it could have been done. His excuse, a very understandable one, was that he just did not have time to embark on such an arduous task or even to supervise another in carrying it out. Laura did, in fact, articulate a number of monosyllables, some of which she used to identify her friends. Lack of funds, as well as lack of time, may also have hampered him. It was not until 1841, with help from a generous donor, that he was able to employ a teacher exclusively for Laura, and Miss Swift must have found her task challenging enough without attempting to teach her pupil to speak.

Laura died in 1889, surviving Dr. Howe by more than ten years. She lived to meet the young Helen Keller, whom Anne Sullivan brought to Perkins.

Since Anne had learned the manual alphabet from Laura, it could be said that Laura also contributed in a small degree to Helen's remarkable education.

Julia Brace, 1807-1884

Although Julia Brace was born 22 years earlier than Laura Bridgman, a clearer idea of her accomplishments and limitations can perhaps be gained if they are compared with those of the younger woman already described.

Julia was born in Hartford, Connecticut, on June 13, 1807. When she was four and a half years of age, she contracted typhus fever, which deprived her of sight and hearing. Until this time, she had been healthy and was apparently of normal intelligence. Like Laura Bridgman, she was skilled at sewing, and like Laura, she mastered the task of threading a needle with her tongue.

As she approached adulthood, it seemed necessary that she should be provided with a home, where all her wants might be supplied, "and her means of happiness, if possible, increased" for the remainder of her life (*American Asylum for the Deaf*, 1837).

With this idea in mind, the directors of the American Asylum for the Deaf (now the American School for the Deaf) in Hartford, Connecticut, received her under their care when she was eighteen years of age.

In 1837, the Asylum reported, "She has now been about 12 years an inmate of the Asylum, and the kind intentions of her benefactors have been fully realized" (*American Asylum for the Deaf*, 1837). Since it was not their intention to educate her, she had serious limitations in communication.

Many reasons have been cited for Laura's "success" and Julia's "failure." Julia had the advantage of a normal life until she was approximately four and one-half years of age, while Laura was only twenty months old when she lost her sight and hearing. Julia had an extremely sensitive sense of smell, which she put to good use in identifying objects and their owners, whereas Laura's sense of smell was defective. Although both families seemed to have done the best that they could with their handicapped children, Laura had the friendly support of Asa Tenney, while Julia was exposed to at least one male member who was described as "unkind." Laura was seven when she was introduced to language, and Julia was at least eighteen. A pathetic difference exists between Howe's description of Laura's eagerness to learn and the Asylum's report that the experiment to teach Julia words "soon became uninteresting to

her" (*American Asylum for the Deaf*, 1837). Julia was apparently influenced by the admitted fact that "it was, of course, very tedious and laborious to her teacher at Hartford."

No one can answer these questions, but subsequent experience with deaf-blind children bears out the importance of early beginnings, and of the necessity of establishing a close relationship between teacher and pupil that rises above tedium. Finally, if a deaf-blind person is to grow in understanding of abstract ideas, and even acquire, as Laura did, a strong religious faith, communication by signs is insufficient, and language development is a necessity.

Other Deaf-Blind Pupils

Dr. Howe had three other pupils during the 1840s. The first to arrive was Lucy Reed, who was born in October, 1827. She entered the school on February 18, 1840. Her eyes were weak from birth, but her hearing was good until she was approximately three years of age. At that time abscesses in her ears destroyed her hearing. She quickly lost the use of words. Her eyes became diseased shortly thereafter, but she was not considered totally blind until she was eight, when she was injured by a rose bush. Little is known of her during the next few years, but her temper was such that she was thought to be mentally deranged. Then she entered Perkins. Dr. Howe describes her "as in a lower stage of humanity than any human being" (Perkins, 1842).

The first few lessons were so stormy that Dr. Howe had to protect himself from being scratched with a fencing mask and gloves. By July, however, she had calmed down and had learned the names of a few objects and how to spell them. How far Dr. Howe might have gone with Lucy will never be known; her parents took her home in July, expecting that she would die within a year and insisting that she should be allowed to do so comfortably at home. She actually lived until August 4, 1904, making her home with relatives and occupying herself with sewing and other kinds of handiwork.

Within a few weeks of Lucy's departure, Oliver Caswell (1829-1896) was admitted to Perkins. He contracted scarlet fever when he was three years and four months old. In six months he lost all power of articulation. As soon as he arrived at Perkins, his thirst for knowledge was shown by his eager examination of everything he could feel or smell (Perkins, 1842).

He had learned some signs, and Dr. Howe's first objective was to stop the use of those signs and introduce him to the names of various objects. He learned more than half a dozen letters in half an hour. Assisted by Laura, Dr. Howe and Miss Swift taught Caswell with the same methods that had been used to teach Laura. He was a passive student compared to Laura and easily satisfied. He remained at Perkins until he was twenty-seven years old. He returned to his home in Rhode Island, where he seems to have lived contentedly until his death in 1896. Laura enjoyed his company and made frequent mention of him in her journal.

The last of Howe's pupils was Almira E. Alden, who was born about 1837. Almira came from Dixmont, Maine, and possessed a little sight. She became deaf when she was seven years old, but she retained her power of speech. Dr. Howe saw in her indications of uncommon intellectual capacity coupled with a strong will and violence of temper far beyond her years.

Laura gave Almira daily lessons, and her comments upon this experience were often quaint and amusing. Beyond the note that Almira went to the American Asylum for the Deaf in Hartford, Connecticut, upon leaving Perkins, no more is known about this child (Perkins, 1847).

Helen Keller Story

Dr. Howe died in January, 1876. He was survived by his famous and successful pupil, Laura Bridgman, whose education, more than that of any other of his clients, had made his name, as well as the name of Perkins, known in many lands. His fame lived on to produce momentous events even after her death. In January, 1842, four years after Laura arrived at Perkins, Charles Dickens, accompanied by his wife, was brought to the school by Charles Sumner. Dr. Howe was not present. According to Miss Rodger, Mr. Dickens "did not deign to notice anything or anybody except Laura," who was there under Miss Swift's care (Howe and Hall, 1904).

Here indeed was a subject suited to Dickens' power of description. In *American Notes*, which he published on his return to England, he tells of his visit. Although Dickens' *American Notes* is probably not widely read today, it was being read 40 years after his visit, even in rural Alabama. In Tusculumbia, the young Mrs. Keller read it and got in touch with Michael Anagnos, the second director of Perkins, asking him if he could provide a teacher for their deaf-blind daughter, Helen.

Anagnos knew of no one who had any experience teaching the deaf-blind. This no doubt worried him less than it would worry us today. Laura Bridgman had been taught by people who learned by doing and by the use of their intelligence and imaginations. Helen Keller would have to manage the same way.

Whether Anagnos really believed that Anne Sullivan, who had graduated a few weeks before, was a suitable person for the task, or whether he suggested her because he could not think of anyone else, is not certain. Anne was available.

Anagnos suggested that Anne read Dr. Howe's voluminous reports on the teaching methods used with Laura, Oliver Caswell, and Lucy Read. Reading these reports took several months and hurt Anne's eyes. Her eyesight varied considerably throughout her life, and she was not ready to travel south to meet her pupil until March, 1887.

Helen, who was then six years of age, had been totally deaf and blind since the age of nineteen months as a result of "acute congestions of the stomach and brain" (Keller, 1904). Anne found that Helen had been very much spoiled by her family and that she was subject to violent tantrums. On one occasion, Helen had overturned her baby sister's cot, and it was feared she might cause serious damage.

The frustration of deafness and blindness has frequently caused violence among children. Laura Bridgman related that as a child she had thrown her cat in the fire. Many deaf-blind children have been equally violent.

In spite of the tantrums, Helen responded to attempts to teach her the names of familiar objects in the manual alphabet. Although at first this was nothing more to her than an interesting game, the significance of what she was learning dawned on her suddenly as it apparently did to Laura Bridgman many years before. Anne Sullivan described the incident in a letter to Mrs. Hopkins (Braddy, 1933).

This morning, while she was washing, she wanted to know the name for 'water.' When she wants to know the name for anything, she points to it and pats my hand. I spelled 'w-a-t-e-r' and thought no more about it until after breakfast. We went to the pumphouse, and I made Helen hold her mug under the spout while I pumped. As the cold water gushed forth, filling the mug, I spelled 'w-a-t-e-r' in Helen's free hand. The word coming so close upon the sensation of cold water rushing over her hand seemed to startle her. She dropped the mug and stood as one transfixed. A new light came into her face. She spelled 'water' several times. Then she dropped to the ground and asked for its name. She pointed to the

pump and the trellis, and suddenly turning around, she asked for my name. I spelled 'teacher.' Just then the nurse brought Helen's little sister into the pumphouse, and Helen spelled 'baby' and pointed to the nurse. All the way back to the house she was highly excited. She learned the name of every object she touched, so that in a few hours she had added 30 new words to her vocabulary.

But if April 5, 1887, was a momentous day for Helen, it was no less for her teacher, not because Helen had at last gotten a firm grip on the key to language, but because that night Helen for the first time on her own accord snuggled into bed with her and kissed her. "I thought my heart would burst, it was so full of joy," Anne wrote. Thus began what has become one of the most famous teacher and pupil relationships on record.

Anne soon began to depart from some of the methods which Dr. Howe had used with Laura Bridgman. Howe was sufficiently advanced not to teach Laura the letters of the alphabet in regular order but to use them in the spelling of words. Anne went much further. She talked to Helen just as she would to a hearing child, not worrying too much whether the words she used were understood or not, which is how normal people learn. From the sound of unfamiliar words, which become familiar with repetition and varied context, they learn to understand their meaning.

We should pause, however, and think of the enormous physical and mental effort that was required to carry this kind of practice. Helen must have read literally millions of words from Anne's fingers. Anne transcribed many textbooks into braille, some of them in foreign languages which she could not understand. The devotion of this teacher has perhaps never been matched by anyone else. The perseverance of the pupil was equally great.

Nobody knows how far Helen Keller would have gone without Anne Sullivan, and it is perhaps idle to speculate. The two of them moved from Tuscumbia, Alabama, to Perkins, where they were in residence from October, 1889, to September, 1893. During this time, Helen learned that a deaf-blind girl in Norway had been taught to speak. Helen at once desired to do likewise. Anne turned to Sara Fuller, the Principal of the Horace Mann School for the Deaf in Boston, who gave Helen a few lessons in articulation. These were carried on four years later at the Wright-Humason School for the Deaf in New York. Many years later (1910) Helen had vocal lessons with Charles A. White at the New England Conservatory of Music in Boston

in an effort to produce a speaking voice which would be pleasing and intelligible to her hearers. Helen was never satisfied with the results and frequently complained that her inability to make people understand her easily was the greatest disappointment in her life. Nevertheless, her friends could understand her, and with a little practice, strangers could also.

Helen had a strong desire to go to college, and to prepare herself she enrolled at the Cambridge School for Young Ladies in Cambridge, Massachusetts, with Anne Sullivan at her side. As the world well knows, she was the first deaf-blind person to receive a bachelor's degree from Radcliffe College, an accomplishment that was not to be repeated for 40 years.

Since Helen Keller's intelligence was unquestionably of a very high order, it is difficult to draw many conclusions from her life in terms of educating the deaf-blind. However, no one doubts the extraordinary influence she has had, not only on persons working with the handicapped, but even more so on the handicapped. Her inspiration has been immeasurable; this fact is supported by countless agencies for the blind and for the deaf throughout the world which bear her name, many of which she helped to establish.

The time has passed, however, when any deaf-blind child can expect the complete devotion and attention that Helen received from Anne Sullivan. Education in the twentieth century has to be put on a broader basis with the task shared by more than one person.

State of the Art at the Turn of the Century

In 1904, William Wade of Pennsylvania, a generous friend of Helen Keller and other deaf-blind persons, printed a monograph that contained the names of deaf-blind persons who had been brought to his attention and a number of significant articles that dealt with the education of the deaf-blind. The monograph is virtually the only source of information concerning the state of the art in America at the turn of the century.

Wade gives some statistics, which, although incomplete and inaccurate, seem to be the best available. He cites 54 deaf-blind persons who lived in America in the nineteenth century. Thirty-five of them, 15 males and 20 females, were still living. Sixteen were still in school, ten in different schools for the deaf, four in two schools for the blind, and two in the Colorado School for the Deaf and Blind. The New York Institution for the Instruction of the Deaf in Washington Heights, New York (now

the New York School for the Deaf, White Plains, New York), and Perkins School for the Blind each had three.

Wade also listed a number of men and women who lost one or both senses after their schooling was completed. Most of these people were deaf first. And he listed some persons who were partially deaf and blind or with one sense entirely lost and the other very deficient.

In his monograph, Wade describes the education of eight deaf-blind girls and boys at the New York Institution for the Instruction of the Deaf, the first of whom, James Caton, born in 1861, was admitted as a deaf pupil in 1871. He lost his sight three years later. His teachers conferred with those at the school for the blind, and a program was devised which included the use of the arithmetic slate and books printed in embossed type and the form of braille known as New York Point. For writing he used a grooved writing board. But the principal instrument in his instruction was the manual alphabet.

Encouraged by Caton's progress, the school accepted a number of other doubly handicapped pupils. In 1883 the class had grown to six pupils, all of them deaf, three of whom had no vision and three who had "vision impaired."

Among Currier's pupils was Stanley Robinson, who was born in Canada in 1865. He became deaf at the age of seven and gradually lost his sight. He is described by Wade as being "of considerable mental ability; he has written for the public, and written well."

Another Currier student was Katie McGirr, who was born in 1880 and lost her sight and hearing as the result of exposure to a blizzard at the age of eight. She learned to read six different type faces for the blind, which was said to be more than any other person living. She seems to have been well educated and was capable of writing a lucid account of her childhood. She was still in school when Mr. Wade issued his monograph.

Wade's monograph also includes detailed accounts of the schooling of several deaf-blind pupils in other schools. Dora Donald reports on her pupil, Linnie Haguewood, at the Iowa School for the Blind in Vinton, Iowa, and the South Dakota School for the Blind. Born in 1879, Linnie lost her sight and hearing from having contracted meningitis at the age of eighteen months. Ada Lyon tells of her young pupil, Leslie Oren, at the Ohio Institution for the Education of the Deaf. Born in 1893, Leslie lost sight and hearing from having contracted spinal meningitis under two and one

half years of age. Anna Gardner Fish tells of Elizabeth Robin, Edith Thomas, and Tommy Stringer at Perkins. All of these pupils received the best of care and made satisfactory progress in school, but for the most part their adult lives are hidden in the obscurity of their families and, occasionally, of institutions.

By the end of the century, the inevitable question was being raised whether the deaf-blind should be educated in schools for the deaf or the blind.

The popular saying that "traditionally the deaf-blind have gone to schools for the blind" is not entirely true. The idea probably came from the fact that of the many deaf-blind persons up until the mid-twentieth century, only the names of Laura Bridgman and Helen Keller, both of whom were associated with Perkins, were known beyond their immediate circle.

Wade, who was a man of strong conviction, makes the case for schools for the deaf but acknowledges the successes achieved at schools for the blind (Wade, 1904).

I am firm in my conviction that the schools for the deaf, and their instructors, are better prepared for teaching the blind-deaf than are the schools for the blind. The very first need of the untaught blind-deaf is power of communication with others—call it language, if you wish. Instilling this is the first instinct of the teacher of the deaf, and is the daily work of such a teacher. The teacher of the blind does not need this. Of course, very many pupils have been taught in our blind schools, and the Perkins Institution for the Blind has crowned itself with glory as the pioneer of the world in it.

In actual numbers, the New York Institution for the Instruction of the Deaf educated as many deaf-blind pupils in the nineteenth century as Perkins did. However, the American Association of Instructors of the Blind (now the Association of Educators for the Visually Handicapped) recommended in 1891 that deaf-blind pupils should be educated in schools for the blind.

Wade, along with other contributors to his monograph, did not think prior experience was necessary to teach the deaf-blind, and he deplored a suggestion made by Helen Keller that she and Anne Sullivan establish a training school for teachers of the deaf-blind. With this exception, he strongly defended Helen Keller and Anne Sullivan against all criticism.

Wade's monograph makes clear that as the twentieth century got under way, educators of blind and deaf were accepting deaf-blind children,

some of them very violent and unpromising, and assigning special teachers to educate them.

Numbers were still too small in any school or at any one time to organize a special department, but on occasion both the New York Institution for the Instruction of the Deaf and the Perkins School for the Blind had special classes.

What Wade did not report is the number of deaf-blind children who, through the ignorance of their parents, never applied for admission to school, or, having applied, were rejected as unsuitable for education.

The Education of Helen Schultz

Helen Schultz, who lost her sight and hearing as a child, was the first woman to succeed to any degree in living the normal life of a housewife. Helen was born in October, 1904, in Jersey City, New Jersey. Of all the people mentioned so far, she is the only one still living at this time (1975). When she was seven she lost her sight and hearing through iritis and spinal meningitis (Hayes, 1926).

The New Jersey Commission for the Blind had a policy of educating as many of its blind children as possible in special classes in the public schools, and Helen was enrolled as a regular pupil. An older child in the neighborhood acted as her guide to and from school.

A special effort was made to keep her articulation as clear as possible, a problem which was made more difficult by the Germanic guttural voice she had inherited from her parents. This effort, however, was so successful that to this day she speaks clearly and is able to deliver public lectures on the deaf-blind. She was taught to read script and printed letters inscribed in the palm of her hand, to read the manual one-hand alphabet, and to read and write braille. She became very expert in all of these.

Helen was then admitted to a special class for girls in the public schools of Montclair and later to a class for the blind in the public schools of Newark, New Jersey, where she completed the eighth grade and devoted much time to handwork and sewing. She shared in household tasks and made many articles of clothing, both for herself and others. Her social life was varied and included membership in church groups.

She eventually married, keeping house for her husband while he farmed in Minnesota. Now that he has turned to different employment in Minneapolis, Helen continues to care for her house and husband very effectively. Her home is spotless; her cooking first-rate. As already mentioned, she

devotes time to lecturing, which she does charmingly and effectively.

Helen was the first deaf-blind woman to accomplish this degree of normality. Although a few deaf-blind women who are completely without sight and hearing since childhood have become self-supporting, none of them has seemed to establish a family life as normal as that of Helen.

Growth at Perkins School

A new chapter in the education of the deaf-blind opened when Inis B. Hall arrived at Perkins in 1931, accompanied by a deaf pupil, Tad Chapman (Perkins, 1932). Miss Hall was a trained teacher of the deaf who had learned from Sophia Alcorn in Detroit the vibration method of teaching speech, which has come to be known as the Tadoma method. The name is a combination of the names of the first two pupils taught in this way, Tad and Oma. The technique involves placing the pupil's hands on the teacher's face and throat so that he or she can feel the vibrations of speech, after which the pupil imitates the same motions to produce speech in return.

This simple description should not obscure the fact that success with the vibration technique depends on endless repetitions of words and untiring perseverance by teacher and pupil alike. Not every teacher has the necessary patience, and a large percent of deaf-blind pupils are incapable of acquiring speech in this manner.

The 1930s at Perkins

The 1930s were a most fruitful decade for Perkins. The success of Miss Hall and others who learned from her in bringing speech to deaf-blind children was remarkable. The lives of a number of outstanding men and women who are alive today have been enriched as a result. They include Tad Chapman, Leonard Dowdy, Carmela Otera, Juanita Morgan, and Robert Smithdas, all of whom speak freely and can understand those who speak to them by feeling the speaker's lips.

Under Miss Hall's leadership, Perkins established the first special department for the deaf-blind large enough to justify the name (Perkins, 1933). Starting with Tad, who was joined in 1932 by Leonard Dowdy, the department had 18 pupils by 1940. The pupils came from a number of states outside New England, including Minnesota, Colorado, Texas, Missouri, and New Jersey.

Some of these children were accompanied by a teacher, who was expected to return with them to their home state after one or two years at Perkins.

This plan, however, was not a success, and nearly all the children who came to the deaf-blind department in Watertown remained there until their education was completed.

Not all of these pupils were totally deaf; some were hard of hearing. All of them received instruction in speech, and a device called the Phipps Unit, which brought sounds to these pupils through bone conduction, was used widely. By this time the department included 13 full-time teachers, but much assistance was provided by other members of the school faculty and by the housemothers in the cottages in which the pupils lived.

A change in the organization took place in the department in the middle of the decade. From the time Laura Bridgman was admitted in 1837, a special teacher had been assigned to each pupil. This practice was modified so that each teacher was given the responsibility for the instruction of two pupils, and an attendant was held responsible for the lives of the two children outside the classroom. The practice allowed the teachers to concentrate on educational matters and gave them the opportunity to compare the progress of the two pupils in their care.

Although Perkins had the largest and best known department for the deaf-blind, a number of other schools were providing instruction to individuals or small groups. Early in the 1930s, through a cooperative plan for increasing the efficiency of instruction for pupils in other schools, teachers from other schools were invited to come to Perkins for visits of three months, during which time their places in their own schools were filled by a member of the Perkins faculty.

Each year Perkins was asked by an increasing number of parents and agencies to accept deaf-blind children. If the department were to respond to all of these requests, larger facilities would be necessary.

In 1937, at the one hundredth anniversary of the arrival at Perkins of Laura Bridgman, an appeal was made for funds to establish a national center for deaf-blind children on the school campus in Watertown, Massachusetts (Perkins, 1938). The appeal, under the now familiar name of Children of the Silent Night, was not widely circulated and was not a success. The effort brought in approximately \$100,000, half of it from a single donor, a sum totally insufficient for its intended purpose.

The plans on which the appeal was based provided space for perhaps 50 deaf-blind children. Although statistics are scarce and unreliable, this was probably far fewer than the actual number of

deaf-blind children in the United States who needed special education. A census reported 379 such persons scattered all over the country, but these no doubt included adults as well as children. Fish estimated that the number might be as high as 2,000 (Fish, 1934).

The idea of a national center was quickly abandoned when the New York Institute for the Education of the Blind in New York City and the California State School for the Blind in Berkeley announced plans to organize departments for deaf-blind children.

The 1940s at Perkins

The teachers of deaf-blind children at Perkins during the decade of Miss Hall's leadership came chiefly from two sources. Some were trained and experienced teachers of the deaf. Most of the others were graduates of the Harvard-Perkins teacher training course, some of whom were partially blind. The war years led to a serious shortage of teachers in the nation's schools for the deaf, a shortage which persisted for a long time after peace came. For more than 15 years the department ceased to grow.

As early as 1941, several admissions had to be deferred because well-qualified teachers for the doubly handicapped were not available (Perkins, 1941). However, at that time 12 children were still enrolled, four of whom had some hearing capability. Thirteen teachers were on the department faculty. By 1951, the number of children was reduced to nine, two of whom came from overseas with their own attendants. The department faculty numbered eight (Perkins, 1951).

During the two preceding decades, a total of 47 pupils had been admitted to the department; 17 pupils were totally deaf and blind, four were blind and hard of hearing, 19 were deaf and partially sighted, and seven had varying degrees of sight and hearing. Of the 17 children who were totally without sight, two were subsequently graduated from Perkins and one from college (Robert C. Smithdas); one was transferred to another school, and three are still at Perkins. With the exception of six, with whom little progress was made, all were instructed to the limit of their academic ability, with special stress on vocational skills. Of this group, 11 had lost their sight and hearing from spinal meningitis, most of them at about two years of age. Of the four blind and hard of hearing, three received high school diplomas from Perkins, and one is still in the school. That deafness is a more serious educational barrier than

blindness is shown by the fact that of the 19 deaf and partially seeing children, none succeeded in graduating and only four made limited progress. Dr. Farrell, Director of Perkins at that time, added, "There may be significance in the fact that nine of the total are rubella cases and of them only one has made any reasonable progress" (Perkins, 1951).

New Departments for Deaf-Blind Children

During the period from 1937 to 1957, seven other departments were organized, five of them in schools for the blind, one in a school for the deaf, and one in a dual school for the deaf and blind.

In 1937, Merle E. Frampton, Principal of the New York Institute for the Education of the Blind, opened the second separate department of deaf-blind children in the United States. In the first year, eight pupils were admitted, and for the next 30 years the numbers averaged about 12. Several of the children earned graduation diplomas at the institute, and one girl proceeded to obtain a degree at Hunter College and returned to join the faculty of the institute (New York Institute, 1957).

As early as 1936, Richard E. French, the Superintendent of the California School for the Blind in Berkeley, sought legislation which would enable him to admit deaf-blind children (Lowefield, 1952). The necessary authorization was not given, however, until 1943. Among the Berkeley pupils was Jacqueline Coker, who proceeded from Berkeley to college and is now successfully employed in Sacramento as a home teacher of men and women who have become blind.

In 1949 Superintendent Wallace C. Finch announced the opening of the department for deaf-blind children at the Michigan State School for the Blind in Lansing. A special feature of that program was its admission of boys and girls at the early age of three years and the counseling of parents of still younger children. The beginning pupils were housed in their own quarters and were moved into the dormitories with blind children as soon as they had acquired adequate communication skills (*The Educational Program for the Deaf-Blind*, undated).

In 1951, Marion Grew, Superintendent of the Washington State School for the Blind in Vancouver, established a deaf-blind department. Children were accepted from other states and from Canada. At times the department had as many as 20 pupils, with six teachers. Several of the pupils are now employed at the Seattle Lighthouse for the Blind (Donaldston, 1975).

So far, all the new departments have been established in schools for the blind. In 1955, the

Alabama Institute for Deaf and Blind opened a Regional Department for Deaf-Blind Children. Superintendent W. W. Elliott stated: "This deaf-blind department is part of the largest complex in the nation for deaf, blind, and deaf-blind children and adults. Students and clients are enrolled from early childhood through adulthood either in an academic or vocational setting" (Elliott, 1975).

The institute occupies an extensive campus in Talladega, Alabama. The deaf-blind department is housed in its own quarters, but whenever possible the deaf-blind children participate in the activities of the deaf or blind children.

For a few years in the 1950s, deaf-blind children were admitted to the Iowa School for the Deaf in Council Bluffs, Iowa. Most of them came from Illinois. With the resignation of the teacher in charge, the department dwindled and was finally closed.

After the Iowa program was closed to out-of-state pupils in 1957, a program was opened at the Illinois Braille and Sight Saving School in Jacksonville. The decision was made that the Illinois Braille and Sight Saving School should undertake the project rather than the School for the Deaf. The precedent for that decision was set by Perkins School for the Blind (Hendrickson, 1972).

The Illinois school was one of the first to make use of the evaluation clinic at the Center for the Development of Blind Children at Syracuse University, New York, which undertook to provide clinical evaluation of deaf-blind children in which "a pediatrician, neurologist, ophthalmologist, speech and hearing consultant, psychologist, and an educational consultant combined their expertise" (Hendrickson, 1972).

Birth of National Organizations

The year 1953 was important in the history of the education of deaf-blind children. The National Study Committee on the Education of Deaf-Blind Children was established. The committee consisted of appointed representatives of the American Association of Instructors for the Blind and the Conference of Executives of American Schools for the Deaf. M. Robert Barnett, Executive Director of the American Foundation for the Blind, served as chairman.

During the next few years, the committee met a number of times, usually in schools with departments for the deaf-blind. Meetings were generally attended only by heads of schools with deaf-blind departments, persons who had a direct concern

with the day-by-day problems of educating doubly handicapped children.

Several hundred deaf-blind children in the United States appeared to be eligible for education. However, at no time prior to the late 1960s were more than 100 of these children in special programs designed for their needs.

Deaf-Blind Child Defined

Perhaps the most important action of this committee was the adoption in the middle 1950s of a definition of a deaf-blind child, which avoided references to specific degrees of deafness or blindness. Experience had already shown that a blind child with a moderate hearing loss, or a deaf child with weak vision, or even a child with partial hearing and partial sight had problems which required special attention. Schools for the blind had rejected children who were hard of hearing, and schools for the deaf had refused to accept pupils with poor vision. It seemed necessary to identify all of these children under a single definition, which hopefully would indicate the need for special programs. Accordingly, a definition was adopted which, with slight modifications in wording, has since been widely accepted in the United States and elsewhere. The definition is used currently by the Department of Health, Education, and Welfare in its guidelines for implementing federal legislation that supports the education of deaf-blind children under Title VI-C of the Elementary and Secondary Education Act. The definition states that a child shall be considered deaf-blind when he or she has auditory and visual defects which make it difficult or impossible for him or her to succeed in regular programs for the deaf or for the blind.

Teacher Training and Research

The continuing difficulty in obtaining qualified teachers led to a decline in the number of pupils enrolled at Perkins. Several children, in fact, had to be released. Fortunately, all of these had some vision and were admitted to schools for the deaf in their home states. In September, 1953, only five children remained with three teachers. Clearly the need was for an expansion of services rather than their diminution.

Since the only college programs for teachers of the deaf-blind were some short summer programs at Michigan State Teachers College in Ypsilanti, Michigan (1949-50), the director of Perkins was authorized by the trustees to establish a program for training teachers of the deaf-blind in associa-

tion with a local university. In September, 1956, the first graduate-level program for teachers of the deaf-blind began under the joint sponsorship of Boston University and Perkins School for the Blind. Nine men and women were enrolled (*Lantern*, 1956).

The effects of this new program were immediate. Six of the trainees from the first class joined the department the following year. Pupil enrollment increased rapidly from six in 1955 to 22 in 1957 and 32 in 1960. Enrollment leveled off, and the number remained at about 30 for the next few years.

The increase in staff made it possible for personnel to be assigned to research, and a beginning was made toward developing more satisfactory evaluation techniques. In November, 1956, Helen Keller dedicated one of the school buildings in honor of her teacher and herself with the three-fold purpose of "educating deaf-blind boys and girls, training teachers of deaf-blind children, and performing research in the education of deaf-blind youth" (*Lantern*, 1956). The Perkins department aimed to carry out these three functions to the best of its ability.

Rubella Wave of the 1960s

The June, 1965, issue of the *Lantern*, house-organ of Perkins School for the Blind, contained an editorial entitled "Do We Face a Rubella Wave?" This editorial, which was based on newspaper and magazine reports, raised the possibility of an unprecedented number of deaf-blind children needing education in the United States in the immediate future and expressed concern over our unreadiness to meet the challenge. Perkins had good cause to be concerned. Most of the other schools that had departments for the deaf-blind were turning to the Perkins school for trained teachers. New programs were not being established; and teacher training schools were showing no interest in the problem.

Several of the schools with deaf-blind departments began to prepare their campuses for an influx of pupils. Perkins immediately started construction on two new buildings, the first structures to be added to the campus for student use since the school moved from Boston to Watertown a half century before.

Foreseeing a need for evaluation of pupils from out of state, one of the new buildings included living quarters for parents of children undergoing evaluation. This building, called the Northeast Building, was ready for use when requests for the

educational evaluation of victims of the 1964-65 rubella epidemic poured in at the beginning of 1970. It also included apartments for an increased number of teacher trainees.

The North Building, which opened later that year, contains classrooms, lecture rooms, and an auditorium. By this time the enrollment of deaf-blind children had risen to 57. Within another year or so, it would exceed 80.

Perkins also reorganized its assignment of teachers to pupils. The plan whereby each teacher had two pupils, usually in a fairly small room, had been practiced 30 years. This was now supplanted by grouping six pupils together with two trained teachers and two untrained teachers' aides. This increased the availability of skilled teachers by 50 percent and prepared the way for the expected influx of pupils. The North Building contains large classrooms to facilitate this plan.

In the *Lantern* editorial referred to above, mention is made of public apathy. The difficulty administrators have faced in providing adequate services for the deaf-blind has been compounded by the mercifully few numbers of such children. One area never had enough of them to rouse people to action. Time and again the argument would be used, both by educators and rehabilitation workers, that their deaf-blind clients were so few that it was impractical to train personnel to serve them. Also the belief that only a rare type of person with high specialized skills could engage in this type of work was hard to overcome.

Federal Legislation Enacted

Early in 1965, the Industrial Home for the Blind and Perkins School decided to hold joint celebrations on the 100th anniversary of the birth of Anne Sullivan. As it turned out, the most important event of the week-long celebration was a banquet given on her 100th birthday, April 14, 1966.

One of the speakers gave an account of the way in which Leonard Dowdy had been taught at Perkins some 30 years before. Leonard was present. A self-reliant, self-supporting man who is able to hold his own in conversation with others, he is an outstanding example of what can be done for a deaf-blind child.

Among the guests was Mary Switzer, then Head of the Vocational Rehabilitation Administration in the Department of Health, Education, and Welfare, who represented President Johnson. Mary Switzer was moved by this account of Leonard Dowdy,

and in November, 1966, discussed with John W. Gardner, Secretary of Health, Education, and Welfare, and Harold Howe II, Commissioner of Education, the possibility of submitting to Congress a bill providing services for deaf-blind children.

By this time, the devastating effects of the rubella epidemic in the United States in 1963 and 1964 were being realized, and the need for swift and decisive action on a large scale was apparent.

During 1967, many meetings were held in Miss Switzer's office with educators of the blind and deaf. At these meetings various possibilities, including direct grants to the states and the creation of a single national center for deaf-blind children, were discussed. However, the final recommendation to the Congress called for the establishment of a limited number of regional centers, each to be coordinated by a local private or public agency. The centers would be responsible for the development of services for the deaf-blind in the areas assigned to them. This legislation was the first of its kind ever to be submitted to Congress.

The bill, which was presented as an amendment to the Elementary and Secondary Education Act of 1965, Title VI-C, was passed by the Senate in November and by the House of Representatives in December, 1967. President Johnson signed the bill on January 1, 1968.

Conclusion

Dr. Howe once wrote, "There floats not upon the stream of life any wreck of humanity so utterly shattered and crippled that its signals of distress should not challenge attention and command assistance." Such words are easily said, but without adequate organization and the support of the community with public funds, the goal cannot be realized. The legislation of 1967 gave hope for fulfillment of Dr. Howe's words in spite of the burden of the worst rubella epidemic on record.

Surely, it was a fortunate accident that Anne Sullivan was born just 20 years before Helen Keller needed her. It was perhaps an even more fortunate accident that she was born just 100 years before a desperate need arose for action on behalf of deaf-blind infants, and celebrations in her honor would bring the whole subject of the deaf-blind to public notice.

The story of Leonard Dowdy was particularly appropriate because it brought this about, for no deaf-blind person has shown more eagerness to "do

something for the deaf-blind." Just by being himself, he accomplished more than almost anyone else.

Great progress has been made in the 130 years since Laura Bridgman came to Perkins. The fact that deaf-blind persons have a right to an education and that suitable programs for their instruction can be devised is widely accepted. In most of the so-called "developed" countries, some deaf-blind children, if not all, are provided with programs of varying degrees of effectiveness. However, there are many areas throughout the world where little or nothing has been done for deaf-blind children.

The rubella epidemic, first of all in Australia and then in western Europe, and finally in the 1960s in North America, has put an end to the first chapter in the education of the deaf-blind and opened another great challenge to society.

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A History of Centers and Services for Deaf-Blind Children

by
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In 1964-65, an estimated 50,000 women contracted rubella, or German measles, during the early months of pregnancy. Some 20,000 of these pregnancies resulted in miscarriages or stillbirths, and 30,000 resulted in children born with one or more handicaps. These handicaps included visual impairments, hearing impairments, mental retardation, and a variety of other physical impairments.

Prior to the epidemic of 1964-65, the number of deaf-blind persons born was estimated to be relatively constant at about 140 per year. However, during the epidemic years the number of children born deaf-blind jumped to more than 2,000.

Rubella is not the only factor contributing to the increasing population of deaf-blind children. An almost equal number of children have been born deaf and blind due to genetic anomalies, congenital debilities and malformations, the improper use of drugs during pregnancy, irradiation, and infectious diseases such as encephalitis and meningitis. Ironically, the advances of medical science have also contributed to this upsurge of multiple birth defects by reducing the infant mortality rate.

The extent of impairment suffered by deaf-blind children ranges on a continuum from profoundly deaf and blind to hard of hearing and partially sighted. To further compound the problems, these children may also have a high proportion of other physical and/or mental disabilities in addition to the combined losses of vision and hearing.

The learning problems of children with dual sensory impairments differ greatly from children having a single impairment of either hearing or vision. The severity of the individual impairment is not what handicaps these children but the overwhelming communication problem that results

from any combination of visual and hearing impairment. Because of this, deaf-blind children cannot be accommodated in special education classes developed solely for the hearing handicapped or for the visually handicapped. Deaf-blind children require education and training designed to meet their special needs.

Because deafness and blindness together had occurred so rarely before 1963, very few services were available at the time of the epidemic. The seven residential programs for deaf-blind children that existed in 1963 enrolled approximately 125 children. In addition, approximately 150 deaf-blind children were enrolled in other public or private programs for the deaf or for the blind.

The 5,000 children born deaf-blind as a result of the rubella epidemic and other causes could not be served by the limited number of deaf-blind programs available. Officials estimated that if facilities for the deaf-blind were expanded to their maximum capacity, they would be able to enroll no more than 450 of these children by 1972.

The sudden increase in the deaf-blind population placed a tremendous burden on existing educational programs. Not only were educational facilities for these children lacking, but also professionals to staff the special programs were needed. It seemed inevitable that many of these children would be inappropriately referred to institutions for the retarded because no programs were available to meet their special needs. Yet, despite the multiplicity of handicaps, functioning ability among these children is widely diverse. Their potentials range from the need for life-time care in a sheltered environment to those who can lead a productive, semi-independent life. A few will be capable of professional training and careers.

These deaf-blind children, like all children, had to be given the opportunity to develop to their maximum capabilities. We know that under the stimulation of an effective developmental program, many handicapped children are able to reach their full potential for development. We also know that the longer a handicapped child goes without meaningful intervention, the more certain it is that his or her future potential will be reduced and the need for institutionalization increased. The provision of early and timely intervention through developmental programs for these children with combined hearing and vision losses was essential if their critical needs were to be met.

Existing programs and facilities would not be able to handle the vastly increased numbers of deaf-blind children resulting from the epidemic. Because of the specialized, extensive services needed by these children and their scattered geographic distribution throughout the United States, pooling the limited resources available and working cooperatively at all levels to solve the problem was essential. A national effort would be required to meet the special needs of these children. Federal support would be necessary to create the new resources that would be needed.

Educators, parents, professionals, and concerned lay people appealed to Congress for help. Thanks to their foresight and tireless efforts and to a sympathetic and responsible Congress, Public Law 90-247, Part C, amending Title VI of the Elementary and Secondary Education Act, was approved and signed into law by President Johnson in January of 1968.

The intent of Congress was to provide through this amendment:

"... A limited number of model centers for deaf-blind children, a program designed to develop and bring to bear upon such children, beginning as early as feasible in life, those specialized, intensive professional and allied services, methods, and aids that are found to be most effective to enable them to achieve their full potential for communication with, and meaningful participation in society, and for self-fulfillment."¹

The goal was to cover all 50 states with ten regional centers. The six or seven existing programs for the deaf-blind were to be the major focal points. Regional centers would be built on the limited existing resources and expertise so that maximum benefit would result. Surrounding states would participate and gradually develop their own programs. Regional areas were established on the

basis of a willingness of the states involved to cooperate and work together.

Private agencies as well as state education agencies were funded by the Bureau of Education for the Handicapped to implement the regional center concept. The agencies were chosen on the basis of their demonstrated interest in and their ability to implement the program conceptualized by the bureau.

Originally, eight regional centers were funded with one million dollars. The amount of funding received by each region depended upon the number of deaf-blind children who could be provided immediate services in that geographical area. Federal appropriations have increased each year and now ten regional centers serve deaf-blind children.

The regional center is not a physical structure in which are provided direct services to children; rather, it is an administrative, organizational, and coordinating unit which utilizes existing resources and develops additional resources as needed to provide diagnostic and educational services to this population. Those states banding together into one region designated a sponsoring agency to serve as the coordinating agency responsible for implementing the regional center program. To achieve greater effectiveness per dollar expended, the emphasis in all centers is on direct services to children in the belief that individual services and specific programs will maximize the deaf-blind individual's potential for independence and thus minimize the total expenditures over that person's lifetime.

Initial efforts required no remodeling or construction, but this does not preclude the possibility that special facilities may someday have to be built to meet the special needs of this group. Such building plans may become necessary at some time and should be considered by each state as they plan for the total service needs of the deaf-blind. The initial emphasis, however, was on quick response to and the delivery of immediate services to meet the needs of these deaf-blind children to reduce the possibilities of their being institutionalized.¹

With these goals in mind, the regional centers began to identify and coordinate every available resource in their region which could be immediately utilized or adapted to provide deaf-blind children the following services, as mandated by law:

1. Comprehensive diagnostic and evaluative services

¹ *Federal Register*, Vol. 40, No. 35 (Thursday, February 20, 1975).

2. A program for adjustment, orientation, and education which integrates all the professional and allied services necessary
3. Effective consultative services for parents, teachers, and others who plan a direct role in the lives of deaf-blind children to enable them to understand the special problems of such children and to assist in the process of their adjustment, orientation, and education ²

The services were to be provided to all deaf-blind children regardless of where they lived. In addition, the following activities were authorized but not required by the law:

1. Research to identify and meet the full range of special needs of deaf-blind children
2. Development or demonstration of new (or improvements in existing) methods, approaches, or techniques, which would contribute to the adjustment and education of such children
3. Training of professional and allied personnel engaged or preparing to engage in programs specifically designed for such children
4. Dissemination of materials and information about practices effective in working with such children ³

While identifying available resources, efforts were also made to identify and locate all deaf-blind children in each region. Obtaining specific information on the population to be served was necessary to plan for appropriate services to ensure efficient use of available resources. This planning information was necessary to facilitate efforts to link the needs of deaf-blind children with services and programs available not only on a statewide basis but throughout the region.

When a child is located, arrangements are made to provide diagnostic and evaluative services by agencies participating in the deaf-blind center program. Data on the child's degree of hearing and vision impairment, degree of functional sensory ability, and degree of additional handicaps must be known and assessed to provide an adequate program for the child's individual needs. The goal in all cases is to determine each child's capacity for growth and development. Upon completion of diagnostic and evaluative services, children are placed in a variety of educational or training programs, including residential schools, training institutions, tutorial programs, public school classes, and preschool programs. The emphasis is

², ³ Ibid.

on providing an individualized program designed to meet the specific needs of each particular deaf-blind child.

The regional centers also provide programs for parents of deaf-blind children. Parent support programs help parents develop an understanding and acceptance of their child's unique problems. Home programs are also used to reinforce and support the child's progress in school programs.

Programs for deaf-blind children have expanded faster than new professionals could be trained. The regional centers have provided inservice training to develop the skills of existing personnel such as teachers, counselors, public health nurses, social workers, and allied professionals to deal with the problems and needs of deaf-blind children and their parents. The centers placed great emphasis on inservice training of teachers to supplement whatever skills they had so that they could more meaningfully and productively work with deaf-blind children.

As a result of the efforts of the regional centers, this country has experienced an unprecedented growth in the number of services available to deaf-blind children. Important strides have been made toward providing deaf-blind persons with opportunities for personal fulfillment and realization of individual potential equal to those enjoyed by their nonhandicapped peers. The success achieved offers an exciting promise for all deaf-blind individuals as the regional center concept continues to develop along with the population it serves. Indeed, "The young deaf-blind population has been more fortunate than the handicapped population in general with respect to institutionalization and federal funding of regional centers for deaf-blind children throughout the nation."⁴

Nearly 12 years have elapsed since the rubella epidemic, and we are now able to measure some of the consequences and evaluate how the regional center concept has worked in response to the demands placed upon it. The crisis was not the epidemic, for, as we have learned since that time, more than half of our deaf-blind children are victims of other causes. The crisis was the lack of available facilities, manpower, and expertise to meet not only the educational needs of these children but also to provide the basic diagnostic and educational evaluative services needed to plan

⁴Brewer, Garry D., and James S. Kakalik. "Serving the Deaf-Blind Population: Planning for 1980." In *1980 Is Now: A Conference on the Future of Deaf-Blind Children*. Edited by Carl E. Sherrick. Los Angeles: John Tracy Clinic, 1974.

appropriate services for these children. Because of our inability to provide developmental services at the critical time, many of our deaf-blind children are in institutions today. We may not be able to foresee or prevent the devastation of a large number of yet unborn children, but we can and must be prepared and ready to respond, should a similar emergency arrive again.

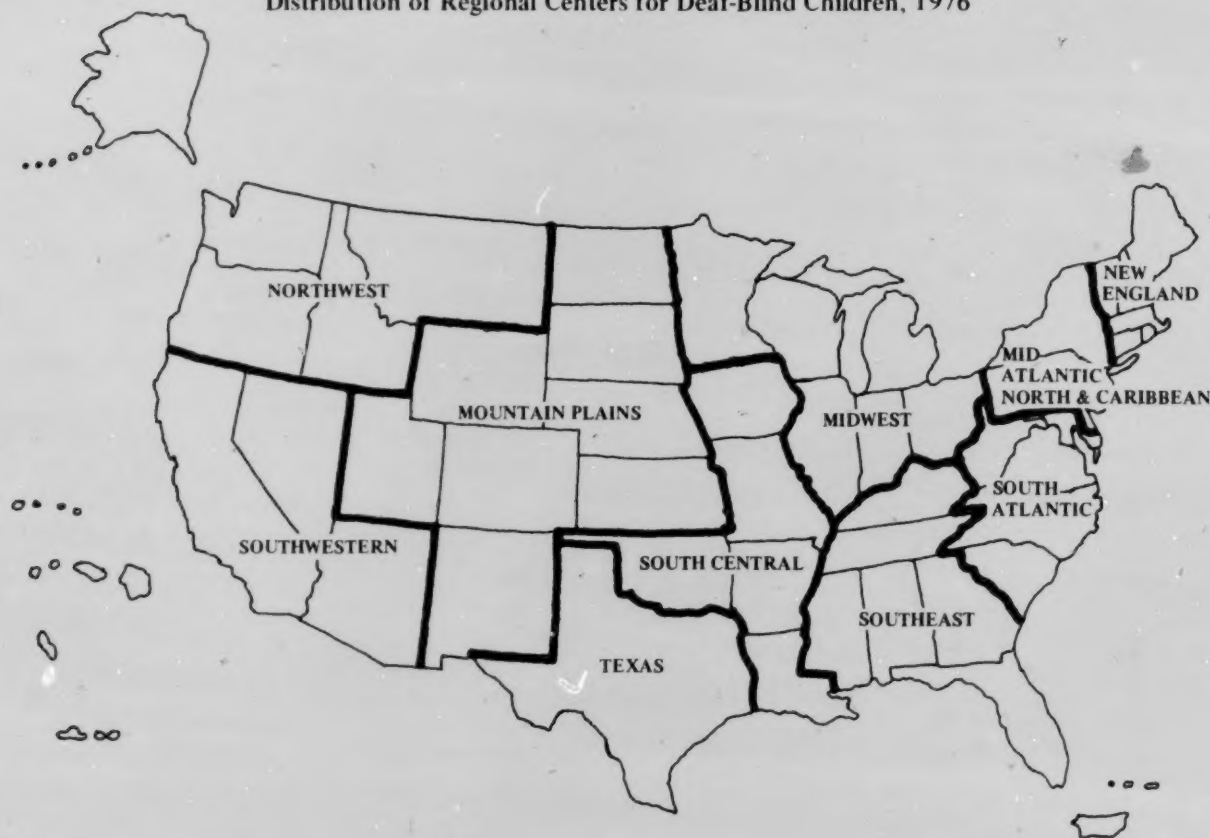
When a cataclysm strikes, leaving a large segment of our population decimated, and the country at large is without the resources or manpower to cope, a regional type of effort to identify, coordinate, and utilize existing resources is needed to meet the needs of the affected population. Persons in all states need to work together for joint resolution of problems of such magnitude. This cooperative effort of states under a regional-type program achieves the goal of delivering services to children sooner and more meaningfully than other efforts. It does not tear children from their families nor isolate them. It permits the delivery

of resources to these children more quickly and possibly saves them from unnecessary institutionalization.

Through such a cooperative effort as the regional deaf-blind centers, each state has been independently strengthened as it developed its own resources for the deaf-blind child. The regional centers have assisted states in developing resources to meet their own state needs and will continue to do so until each state can provide for itself. Some states will continue to need regional cooperative efforts longer than other states. The role of the regional center will change slowly as the needs of the states and the population it serves change.

Federal creation and support of the regional centers was initially required because of the scarcity of services and the overwhelming costs involved. However, with the assistance of the regional centers, most states have now developed their own resources to meet the educational needs of this population. Educational programs are pro-

Distribution of Regional Centers for Deaf-Blind Children, 1976



Total Funds Approved Regional Deaf-Blind Centers Fiscal Year 1969-1976

Regional Center	Program year 1969-1970; fiscal year 1969	Program year 1970-1971; fiscal year 1970	Program year 1971-1972; fiscal year 1971	Program year 1972-1973; fiscal year 1972	Program year 1973-1974; fiscal year 1973	Program year 1974-1975; fiscal year 1974	Program year 1975-1976; fiscal year 1975	Program year 1976-1977; fiscal year 1976
Alabama	\$ 150,250	\$ 202,000	\$ 300,000	\$ 795,000	\$ 875,000	\$ 1,122,363	\$ 933,206	\$ 1,430,000
California	189,000	337,760	677,000	975,000	800,000	2,005,000	1,348,306	1,941,424
Colorado	36,260	250,000	450,000	800,000	1,302,000	2,019,228	1,640,712	1,774,778
Massachusetts	177,525	279,855	410,415	700,000	875,000	1,093,750	925,000	1,248,034
Michigan	50,000	109,736	437,000	875,000	979,000	1,585,955	1,451,764	1,927,583
Minnesota	—	50,000	249,998	350,000	535,000	—	—	—
New York	189,000	280,000	460,000	830,000	1,478,000	2,050,000	1,925,000	2,509,260
North Carolina	—	50,000	275,000	550,000	849,000	1,225,000	1,199,209	1,815,660
Texas (Callier-UTD)	51,039	290,000	790,587	975,000	1,132,726	1,380,697	1,018,400	1,466,400
Washington	156,926	150,649	450,000	650,000	847,000	1,155,548	924,435	1,132,907
Texas Educational Agency	—	—	—	—	327,274	417,459	633,968	753,954
Total	\$1,000,000	\$2,000,000	\$4,500,000	\$7,500,000	\$10,000,000	\$14,055,000	\$12,000,000	\$16,000,000

vided in all 50 states, the Trust Territories, Puerto Rico, and the Virgin Islands. The number of state and local dollars allocated for deaf-blind children has increased and at the present time less than half the total cost of education for deaf-blind children comes from federal monies.

These educational services must meet not only the needs of deaf-blind individuals as children but also their changing needs as they reach adulthood. With the exception of the registry maintained by the National Center for Deaf-Blind Youths and Adults, no information on deaf-blind persons above the age of twenty-one is available. However, as the nation's deaf-blind population increases in age, information relating to the prevalence of hearing and vision impairments will likely also increase. This means that not only do services need to be provided for children born deaf-blind as a result of the rubella epidemic but also the same educational services and rehabilitation services may be in demand by a far greater number of deaf-blind adults as well.

Public Law 94-142, which goes into effect in 1978, requires that federal monies be distributed to the states to provide for case finding; identifi-

cation; and diagnostic, evaluation, and educational services for the severely handicapped child who is unserved. In time, this may allow Title VI-C funds, which are now supporting those educational programs under the supervision of regional centers, to be redirected to meet other program needs which states cannot provide for themselves, such as vocational education and the development of alternative residence programs to promote deinstitutionalization.

Such a comprehensive service delivery system, coordinated by the centers in cooperation with the states, would allow opportunity for the individual to be mainstreamed into the community or to return to shelter that is always there for that individual in the event he or she wishes to return. To enhance the chance of successful community integration, however, the regional centers can coordinate, plan, and assist the states in utilizing the various services available to the deaf-blind. This assistance will allow regional centers and the states to combine their resources, including those of the National Center for Deaf-Blind Youths and Adults, to provide the comprehensive continuum of services necessary to sustain the deaf-blind individual throughout his or her lifetime.

European Programs for Deaf-Blind Children: An Overview

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During the nineteenth century four European countries developed services for deaf-blind children. These were France (1860), Sweden (1882), Germany (1887), and Finland (1889). France is given credit for having established the first school for the deaf in Europe (1760) and the first school for the blind (1784). Not knowing about the successful education of Laura Bridgman at the Perkins School for the Blind in Massachusetts, France made the first European attempt to educate a deaf-blind child.

Early Efforts

In 1860 a Catholic school for deaf girls at Larnay near Poitiers accepted Germaine Cambon, a deaf-blind girl. A second child, Marthe Obrecht, was accepted in 1875. Three more girls were later enrolled: Marie Heurtin in 1895, Anne-Marie Poyet in 1907, and Marthe Heurtin in 1910. Thus, five girls were given some education during the first 50 years of the French program.

Anne-Marie, who had become deaf-blind at three years of age, developed fairly good speech and, after six years of instruction at Larnay, returned to her parents' home. She obtained a job in a nearby factory making shoelaces and braided cords.

Marie and Marthe Heurtin were sisters who had become deaf-blind several years apart. Both learned the manual alphabet, braille, typing, and independent daily living skills. Marthe was introduced to grammar, history, geography, and religion. She was still living at Larnay School when she was described by Arnould (1948).

In 1882 Queen Sofia of Sweden asked Elisabeth Anrep-Nordin, a teacher at the school for deaf children at Skara, to take care of a ten-year-old deaf-blind girl. Within the next four years, three more deaf-blind children were brought to Mrs.

Anrep-Nordin. The school later was moved to Vanersborg.

Among the children who were brought to Mrs. Anrep-Nordin, there were many who appeared to be mentally retarded or who had physical handicaps in addition to either deafness or blindness, and the institution opened its doors to many kinds of multihandicapped children. By 1905 a workshop for adults was constructed, and in 1906 a ward for severely retarded blind children was added.

At first the school was funded partly by state and local subsidies and partly by voluntary donations. In 1901 the Foundation of Queen Sofia was established for the purpose of providing new buildings. The entire institution, including the school, the workshop, and the ward for severely retarded, subsequently was called the Foundation of Queen Sofia.

By 1922 the institution was transferred to Lund and taken over by the state. In 1965 the school unit was detached from the institution and was moved to new buildings at Örebro, where it now functions as a school for multihandicapped blind children including the deaf-blind.

From the time Mrs. Anrep-Nordin agreed to work with the first deaf-blind girl in 1882, Sweden has had a continuous program for deaf-blind children, with the exception of a short period, 1957 to 1962, when no deaf-blind child was known to exist.

Germany offered its first help to a deaf-blind child in 1887, when the Reverend Theo Hoppe of Potsdam/Babelsberg began teaching Hertha Schulz. Four years later an experienced teacher of deaf children, Gustav Riemann, joined Reverend Hoppe, and more children were accepted. The original institution in Potsdam/Babelsberg recently cele-

brated its one-hundredth anniversary and now offers services to the deaf-blind children of the German Democratic Republic.

The fourth early program was started in Finland in 1889 by Anna Haickel; it was carried on by E. Knappe after 1894. Two world wars interrupted service.

Development of Modern Services

As special education programs for many types of exceptional children were expanded and refined in Europe, children with combinations of vision and hearing losses were gradually accepted under numerous administrative plans. The placement of these deaf-blind children in these programs came about in a variety of ways: (1) national planning, a feeling of obligation to help known deaf-blind children by the administration or even by one teacher in certain institutions; (2) a recognition that new services for multihandicapped deaf or multihandicapped blind children should include the deaf-blind as well; and (3) by default when it seemed that no one else would accept the children. (See Table 1 for historical development of services for the deaf-blind in Europe, and see the addresses of current European programs for deaf-blind children at the end of this paper.)

The patterns of funding used to start new programs are often maintained as the programs become an accepted part of the country's special education efforts. Financial support is usually a divided responsibility, and most schools continue the search for broader financial help. (See Table 2 for financial support of services for the deaf-blind.)

In early 1975 about 350 deaf-blind children were enrolled in school programs. Great differences exist in the ratio of children served to the general population of each country. The reasons might include the following: (1) proportion of severely handicapped deaf-blind to so-called classic deaf-blind; (2) willingness and ability to help children who present enormous problems; (3) patterns of case finding; and (4) financial problems. (See Table 3 for distribution of deaf-blind children in European school programs.)

A rough grouping of the 276 children whose ages were obtainable shows a developing trend; i.e., services should begin as early as possible and should extend well beyond the normal school-leaving age, which is between fourteen and sixteen years in European countries. (See Table 4 for ages of persons served by programs for the deaf-blind.)

What do the European programs for deaf-blind children have in common? What sort of profes-

sional relationship exists among the staffs of the several schools? What connection have these programs with organizations for the deaf or the blind?

Great Britain

The largest number of European children with combined vision and hearing losses is served in Great Britain. Compared to the thousands in the United States, the 101 deaf-blind children in Great Britain seem like very few. Yet this is almost twice the number in school in Western Germany, whose general population is approximately 6 percent more, and it is twice the number in school in Russia, whose general population is almost 200 percent greater.

Condovery Hall School for Blind Children with Other Handicaps is best known of the centers. This school is in the village of Condovery, near the larger city of Shrewsbury, in the County of Shropshire. It was established in 1947 by the Royal National Institute for the Blind as a school for multihandicapped blind children. The main building is a late sixteenth century Elizabethan mansion in the center of several acres of manicured rolling lawns with trees clipped in designs. A more beautiful setting for a school could not be imagined. The modern buildings, which have been attached to the main hall or placed on another section of the property, were skillfully planned so that they provide needed facilities without detracting from the magnificence of the original house.

S. O. Myers became the first director of the school, and during more than 20 years of service he left his stamp indelibly upon its philosophy and practices. Upon his retirement, he conducted a follow-up study of 314 graduates. The study showed how strongly the school had influenced its former students, helping many of them to achieve adult lives of dignity in families and communities (Myers, 1975).

In the last few years, the population of the school has been a little under 130, including the section for deaf-blind children called Pathways, which has been directed by Joan Shields since its creation. The goal is to provide the children with the means of living happy, full lives to the limits of their capacities now and in the future. A warm, personal relationship exists among the teachers, houseparents, and children. The curriculum is based upon understanding the demands of daily living, learning about and participating in the life of the nearby community, enjoying and caring for pets, and functioning as independently as possible.

The deaf-blind children generally enroll at Condo-ver Hall some time after age seven, having spent their early years at Overley Hall, a school for young blind children in Condo-ver Village. The Royal National Institute for the Blind used to administer six Sunshine Nursery Homes for young blind children from about two-and-one-half years of age to ten. Overley Hall was one of those homes. Gradually it changed character as it accepted more and more multihandicapped young blind children. Now it enrolls only the younger deaf-blind children. The general functioning of a child is the main determinant as to who will stay at Overley until eleven years of age and who will come to Condo-ver Hall earlier. Overley Hall assumes as part of its role the assessment of all deaf-blind children.

Language instruction at both Overley and Condo-ver is given in the Paget-Gorman system, which was originated by Dr. Paget and elaborated by Dr. Gorman, an Australian deaf man. The Paget-Gorman language system for the deaf is an arbitrary sign language referring to objects, situations, and actions. At present more than 2,000 signs are used, and Dr. Gorman continues to create additional ones.

Most schools for the deaf in England use this system for young children; however, the children generally convert to oral language and/or finger-spelling between the ages of five and ten years. The deaf-blind children at Condo-ver Hall have been kept on the Paget-Gorman system, but they have a great deal of oral language with or without the Tadoma method as enrichment. What is important in the education of deaf-blind children is the opportunity for dialogue between a child and his or her world—regardless of system. Many of the children at Pathways manage to communicate very well with the adults in their lives.

Lea Hospital in Bromsgrove is a residential center for blind children and adults who are severely retarded. In reality it is not a hospital at all. The word is used in preference to "institution." Whatever the categorizing name, it is surely one of the finest places of its kind in the world. Directed by G. B. Simon, a psychiatrist, the center is spacious, with groups of low structures over an immense tract of rolling hills. The buildings range from old-fashioned, inconvenient ones which have been remodeled and/or redecorated, often by staff and residents, to exceptionally modern buildings planned to meet the demands of the residents, whose extensive activities include sports, sheltered workshops, and social clubs.

The school, directed by John Southwell, has a curriculum as varied as the staff can make it. The majority of the young people in the school may spend their lives in the institution, yet the program is full of activities designed to prepare them to participate as fully as possible in the lives of their families and communities during the periods when they are home. Probably because of the concrete assistance in daily living activities, social skills, work habits, and self-management, a high percentage of the young people have left the institution and have been successfully integrated in normal communities.

The section for deaf-blind children accepts only those children who cannot succeed in Condo-ver Hall or in other programs in Great Britain. Their level of functioning is the lowest described in professional literature. Instruction for them is strongly self-care, household tasks, and leisure-time activities. The children are often taken on trips to nearby shops, homes, and areas in the neighborhood.

Inservice training sessions are conducted for the staff, and research is largely in the areas of assessment and programming. Behavior modification techniques have proved largely successful.

An English Legislative Act in 1971 made it mandatory to provide education to all children in England. Lea Hospital demonstrates admirably that education can take place at any level.

In London a day program for seven young children is conducted in a regular elementary school (Paddock Junior School). This particular unit was started in 1965 for two children in part of a hospital ward and later transferred to a section of a school for the sighted. The instructor, F. J. Dale, has worked under difficult circumstances. With little classroom or playground space, isolated from other special education programs and with minimal ancillary help, he has offered training to certain children who seemed not to fit elsewhere and to others who would benefit most from living at home.

At present 23 children are enrolled in nine other schools within the Inner London Education Authority.

The Royal Victoria School for the Blind at Newcastle-on-Tyne has a unit for eight deaf-blind children under the direction of Anthony Best. The curriculum is a realistic, practical one carried out through the combined efforts of teachers and house staff.

New programs are either ready to be launched or are already functioning in Leeds, England, and in Scotland.

German Democratic Republic and German Federal Republic

One of the results of the division of Germany was the placement of the unit for deaf-blind children in the German Democratic Republic (East Germany). For over 100 years the Lutheran Church has maintained a multipurpose center for handicapped children and adults at Babelsberg near Potsdam. Today Reverend Eckard Beyer directs the institution, which has a school for physically handicapped, deaf, and deaf-blind children; a hospital staffed by specialists in orthopedics with a large outpatient service; residences for children and adults with many types of handicaps; sheltered workshops; and a home for old people, including several who are deaf-blind.

The facilities are cramped, unattractive, and generally unsuitable to modern programs. Nevertheless, some unusually fine projects are carried on. For example, one large workshop serves as the only manufacturing center in the German Democratic Republic for artificial limbs, specially constructed shoes, and braces.

The unit for deaf-blind children includes some children who might better be placed in other types of educational programs, personnel who are generally inadequately trained, and minimal equipment and personnel. For example, one young teacher instructs deaf-blind children during the day, is responsible for their free-time activities outside of class, and sleeps in the unit to be on call at night.

The staff of the institution consists of two broad categories: unmarried Lutheran deaconesses who wear habits; and secular persons who usually live in the community. Despite the different life-styles of the two groups, a strong spirit of unity exists among the staff, as well as a sense of mission and a willingness to give the last measure for the community of handicapped persons.

In 1965 K. H. Baaske, a teacher at the school for blind children in Hanover, West Germany, initiated the steps leading from acceptance of a few deaf-blind children in his school to what is now the independent, luxurious school he directs. Fifty-three children are enrolled. In addition to the 48 who have been rejected in the last five years, there is a long waiting list of 110 other known deaf-blind children on a national registry.

The center for deaf-blind children is affiliated with many other nearby institutions for the blind, including a school for blind children and a residential community for blind persons and their families. The center includes vocational training units, workshops, adult-education programs, and hostels. From counseling parents of blind babies through the full range of possible services and programs, including care of the aged, the number and variety of facilities and services offered probably make this center in Hanover the most comprehensive and highly organized community of blind persons in the world.

A visitor to the school for deaf-blind children is almost overwhelmed by the abundance of equipment. Devices have been developed which make it possible for a deaf-blind person to answer a telephone and receive the message in braille, to communicate from room to room, and to live with a sense of community rather than with the isolation that envelops many deaf-blind persons, even in centers that are constructed for their care and education. With a philosophy that includes life planning and service in special settings, the curriculum is geared to self-care, physical activities, communication, and handicrafts that will enable the deaf-blind child to participate later in the life of the community of the blind.

The teachers at the school are highly educated. They are required to have had teacher training plus one and a half years of experience with normal children; two years of internship at the school for deaf-blind children (one year before and one year after special university study); four terms of study at the department of special education at Hamburg University; and, if possible, the special course at the Instituut voor Doven in the Netherlands in the education of deaf-blind children.

The school has been unusually active in publicizing its work to the country at large via radio, television, and newspapers. This may have contributed strongly to the tremendous success in fund raising.

U.S.S.R.

Teachers for deaf-blind children in the Soviet Union generally are trained in Moscow at the Institute of Defectology, one of a dozen institutes under the Academy of Pedagogical Sciences. Research projects on teaching techniques, equipment, and programs are conducted there in connection with a demonstration school whose pupils (mentally retarded, blind, deaf, and deaf-blind) live in dormitories (Watkins, 1973).

The national school for deaf-blind children opened in 1963 at Zagorsk, 45 miles from Moscow. About 50 pupils from three to twenty-three years of age are taught in groups of three. Three adults, a combination of teachers and assistants, work with each group using methods developed by A. I. Mescheryakov and his associates at the Institute of Defectology. Communication is taught through natural signs and manual cues in connection with oral language and lipreading. The system is quite different from the Tadoma method. The children develop exceptional use of language through speech, one-handed fingerspelling, braille, and letter-printing in the hand.

In contrast to oral approaches used in a few other countries, the program at Zagorsk does not place so much emphasis upon speech that little time is left in a school day for content. School subjects and vocational training are also offered. Recently three seniors from the school (twenty to twenty-two years of age) passed the normal entrance examinations to the University of Moscow, two in psychology and one in philosophy (Mescheryakov and Apraushév, 1975).

Understandably, the great majority of pupils at this school are in the classical category of deaf-blind children; few are rubella youngsters.

Scandinavian Countries

Lumping together the four very different programs one finds in Sweden, Denmark, Finland, and Norway is not entirely reasonable. The commonalities occur mainly in the philosophy concerning the right of all children to service and in some of the educational procedures, probably brought about by frequent workshops held for teachers of the deaf-blind in these countries.

Sweden has legislation making education compulsory for all children, including the deaf-blind, and has recommended placement in centers other than the program for the deaf-blind for very few children. In Norway and Finland legislation makes it possible to offer services to the deaf-blind providing, in professional judgment, the children can benefit from it. All who have been identified and who have applied for service have been accepted. Denmark has no special legislation but within the last five years has been able to keep all except two deaf-blind children in its program.

Sweden. The school for multihandicapped blind and partially seeing children in Örebro, Sweden, is named Ekeskolan, which means Oak School. When the buildings were constructed in 1965 near a woods, many trees were sacrificed, but one magni-

ficent oak was left standing. Most of the pupils have sat in its shade or climbed its welcoming branches.

Ekeskolan has the responsibility of accepting all visually impaired children with additional handicaps. The board must find suitable placement for the very few it rejects. Generally, even the most difficult children receive one to three years of training, observation, and evaluation before the decision is made to relocate them. Even after a new placement is made, it is not unusual for the personnel from Ekeskolan to maintain contact and offer assistance. For example, when four severely retarded deaf-blind children were placed in a home for the mentally retarded, the teachers from Ekeskolan trained a staff in that home to care for and teach the children.

Of the 14 deaf-blind children at Ekeskolan early in 1975, 13 were affected by rubella. Emphasis is placed upon motor development, language, self-care, experience in community functions, prevocational activities, and summer and winter sports. Parents participate in a guidance program to learn how to help the children keep their places in the families and to make it possible for them to function in some sort of work situation as young adults.

An interesting experiment in community living has proved highly successful. In the autumn of 1972, five adolescent deaf-blind boys and girls were moved into a five-room apartment in a new district of Örebro. A couple, serving as houseparents, live in the adjacent two-room apartment, and a door connects the two residences.

Each adolescent is assigned household tasks, including shopping, and they all travel to school and home by local buses. One of the members of this "family" is Anna, an eighteen-year-old rubella girl who has a hearing loss of 80 decibels in both ears and residual vision of 20/120 in her one eye. She has now lived three academic years in the apartment. During the first two years, she shared a room with another rubella girl with whom she got along very well. At the end of her second year, Anna was considered ready to leave Ekeskolan, and she was enrolled in a high school for normally seeing and hearing children. Anna's program and subjects have been adjusted a little to suit her, and she travels to school alone by bus even though she has to make one transfer. She is not dependent upon her schoolmates and is proud of her ability to manage by herself.

Anna has continued to live in the home where she has good relationships with the other deaf-

blind young people and with the houseparents. During her third year she was given a private room, which she has decorated according to her personal taste and which she keeps in good order. Every fifth day she takes her turn at common household tasks, having learned to use the washing machine, assist with ironing and mangling, set the table, prepare simple foods, and clean up the kitchen.

Once a week Anna returns to Ekeskolan to participate in Girl Scout activities. Now and then she takes part in various functions at a youth center in town. Although she is the only deaf-blind person who goes there and her speech is quite poor, she finds it easy to make contact with people.

On occasion the five adolescents invite guests to the apartment. Anna and her housemates contribute to the preparation, welcome the visitors, and serve them coffee and sandwiches. All the young people are happy to live in the apartment, and for Anna the experience has broadened her life and given her a feeling of independence (Sandstrom, 1975).

Denmark. The program for deaf-blind children in Denmark was opened in 1965 at the state school for the deaf in Aalborg. The first teacher, Lars Guldager, had been trained at Perkins, and he provided the impetus necessary to carry the program forward despite changes of staff and the presence of children with great problems. The present director of the department, Karen Anderson, was also trained at Perkins. She has developed research, teacher-training courses, and a journal for teachers of deaf-blind children.

Ten of the 11 children enrolled in early 1975 were affected by rubella. The Danish program has never had a child of the classical type. In recent years it has been possible to identify the children earlier, and home-training is emphasized for both the children and their parents. At present five preschool children from one to six years of age are taught in their homes. Once a year the children spend two weeks at the school with planned activities for both deaf-blind children and their parents. Also, special courses for parents are offered at the school during the year.

Being located in a school for the deaf has had advantages. All personnel have a solid knowledge of language development and learning problems for the deaf. Everyone must know manual and sign language as well as oral language. The houseparents are well-educated people who have had training in the education of the deaf.

When the school needed more dormitory space, school officials resisted building another large structure and elected to buy eight homes in communities near the campus. Groups of eight to ten children, including some of the deaf-blind, were placed in these houses with adult supervision. Despite predictable problems community living has fostered social activities in the neighborhoods, knowledge of shops and businesses, awareness of responsibilities in family life, and more independence.

Finland. Service is provided to deaf-blind children in Finland in a number of institutions and in their homes. While only four (ages six to seventeen years) are enrolled at the school for the deaf in Haukkala, 11 others (from infancy to eleven years of age) are helped by a consultant who counsels parents and goes to hospitals and institutions for the mentally retarded where some deaf-blind children reside. The usual gap in service during adolescence is filled by another consultant who works under the Central Organization of the Blind and who organizes courses, recreational activities, and social gatherings. This person also ensures that any further medical or psychological help is provided.

Norway. In 1963 the Hjemmet for Dove (Home for the Deaf) in Andebu accepted its first deaf-blind children. As a school and home for multi-handicapped deaf, the center was already staffed with personnel accustomed to working with deaf children with many handicaps. In fact, a young psychiatrist, T. Basilier, had become so interested in this community that he learned the communication systems used there and devoted his full time to helping the deaf.

This community for the deaf includes schools, vocational training courses, and sheltered workshops. The surroundings of the school include farmhouses and wooded areas which are used as means of learning about the world outside the center as well as for social and physical training. The small family units offer good opportunities for instruction in daily living skills and foster awareness of social obligations.

Switzerland

In 1967 Switzerland had one deaf-blind child in a school for the mentally retarded. She was under the care of a teacher who had worked with the girl privately long before the school accepted her. A second deaf-blind child was being educated privately by a Perkins-trained teacher. In addition, a

blind music teacher had developed a day program of care and instruction in her home for a number of multihandicapped blind children including a few deaf-blind youngsters.

In 1969 Sonnenberg School for Blind Children in Fribourg opened the first formal class for deaf-blind children. The program was directed by Hubert Cardinaux and his wife. Under the direction of Dr. Cardinaux and his wife, the program grew rapidly and soon moved away from the school into a rented space in a regular apartment building. Using one apartment as classrooms and a second apartment as dormitory space, the little school for the deaf-blind lost most of its identification with the large school for the blind and became part of the life of the apartment building and the community. Although the entire staff has a feeling of professional isolation at times because of the school's unusual setting, they agree completely that the children have benefited enormously from a surprising amount of integration in the neighborhood (Cardinaux, 1975).

In 1975 the school's ten pupils (three to eighteen years of age) participated in a strong program of physical education, language instruction, daily living skills, and neighborhood activities. The school has an extensive preschool program and conducts systematic research on assessment. The ten children require a staff of three teachers and six assistants working full time plus two part-time teachers.

The second of the two existing Swiss programs was opened in Zurich in 1970 by Dorothea Goldschmid. Eight pupils with an age range extending to eighteen years are served by two full-time and four part-time teachers. They are grouped in small families in the living quarters. The director, Daniel Giger-Baumgartner, is currently conducting research on teaching techniques and assessment.

A recent survey of the German-speaking part of Switzerland resulted in the identification of 50 deaf-blind children not presently in educational programs. To include many of these children in the present facilities will be difficult.

Spain

The organization of blind persons in Spain, Organización Nacional de Ciegos, coordinates all schools, rehabilitation centers, workshops, and other services for blind children and adults. The organization has considerable wealth and is generous not only to Spanish blind persons but also to those in other countries. Among its programs is a

department for deaf-blind children in a school for the blind in Madrid.

The six young deaf-blind people enrolled are all classical deaf-blind, one being about seven years old and the rest between twelve and twenty-five years of age. One teacher handles the department and has concentrated her efforts on self-care, language, reading in braille, and physical activities. The deaf-blind children participate with the blind pupils in prevocational courses dealing with carpet making, wood and metal work, electrical work, and handicrafts. The deaf-blind young adults generally enter job training for bookbinding, carpet weaving, and tasks in a braille printing plant.

The Spanish program has been successful in placing deaf-blind persons in gainful employment positions and in helping them to function well in their personal lives.

France

France's program for deaf-blind children is located in the same school for the deaf that was begun in 1860. However, new buildings adjacent to the main school make possible the modern program which was started in 1968. Although the large school is for deaf girls only, the program for the deaf-blind accepts both boys and girls.

The 25 children in the program are between six and twenty-three years of age. The majority have the rubella syndrome. Ten full-time teachers are employed. A large problem is the planning for vocational training and future employment for the adolescents, most of whom are severely handicapped.

The present director, Mr. Souriau, is a psychologist who is particularly interested in improvements in general teaching methods and language instruction. In the last few years, the program has made great progress in training its staff and in developing close relationships with the parents of the children.

Italy

A chance meeting of a capable young deaf-blind woman, Miss Santilli, and a priest interested in special education, Father Dino Marabini, resulted in the creation of a small school for deaf-blind children in Osimo, near Ancona, in 1967. The school was financed through contributions from national and local governments and private organizations. Today, the school, called Institute Nostra Casa, is under a broad organization, Lega Del Filo D'oro, which has many special education and rehabilitation projects. Twenty-six children

between six and twenty years of age are served by a full-time staff of 11 teachers and 37 assistants.

The program has been influenced a great deal by the Instituut voor Doven in the Netherlands, where the present director of Nostra Casa spent six months studying the methods used with deaf-blind children. The amount of ancillary staff available to the school is extensive. Part-time services of doctors, psychiatrists, university professors, and specialists in various subject matters have increased the general knowledge and functioning of the staff considerably. Despite great financial problems, the school is moving rapidly toward a degree of excellence.

The Netherlands

The Instituut voor Doven (School for the Deaf) in the village of Sint Michielsgestel near 'sHertogenbosch, Netherlands, was opened in 1840. In 1961 the director, Father Johannes Van Eijndhoven, decided to accept some deaf-blind children in the department of multihandicapped deaf children, and Johannes van Dijk was given the responsibility of developing a program.

At present 25 children from four to twenty-one years of age are served by a staff of eight teachers. In addition, 20 full-time child-care workers serve on a split assignment basis. They assist the teachers with the children during the classroom hours, and they take care of the children when they are not in class. The relationship of the teachers and child-care workers is such that continuous and systematic instruction is possible during the child's waking hours.

The School for the Deaf has full-time specialists who also provide care for the deaf-blind children. These include an audiologist, otologist, ophthalmologist, orthopedist, and a general practitioner. The custom of the institution has been to provide training courses for new staff members, so it was natural that training should be arranged for the personnel for the deaf-blind department as well.

Under the direction of Dr. van Dijk, the staff has studied ways of analyzing the children's problems and has planned the procedures to be used. In the 14 years it has been operating, the program has changed considerably as philosophies and practices have been modified and as space, equipment, and staff have become available.

The staff has tried to gain insight in three major areas: motor activity as a basis for development, behavior in relation to people and the environment, and communication.

Motor activity. In the early program at San Rafael, the department for deaf-blind children at the Instituut voor Doven developed a strong program of motor activities. Because motor behavior appears highly limited in untrained deaf-blind children, San Rafael began by having a teacher move the child's body and then moving with the child in what came to be called "coactive movement." The proximity of the teacher's body usually provided the needed stimulation so that the child gradually became interested in the varied motor experiences. Repeating patterns and series of movements led the child to anticipate the next movement and to initiate part of the action.

Anticipation is very important, because the child is, for the moment, involved in the external environment. One can then introduce signal behavior such as touching the child's head to indicate that the next action will be a somersault.

Imitative behavior can be fostered through motor activities, and modern literature on the development of language in children emphasizes the strong relationship between imitative behavior and learning in general.

Motor activity in patterns can contribute to improvement in short-term memory, one of the major problems in teaching the deaf-blind. Counseling of parents of very young deaf-blind children could provide ideas for teaching motor patterns that will influence the evolution of short-term memory.

Rhythm plays a vital role in deaf and deaf-blind children in remembering temporal ordering. Because hearing is closely related to perception of temporal ordering, a motoric program for hearing-impaired children should be a motoric-rhythmic-auditory training program. Language development is dependent to a large degree upon rhythm, particularly upon rhythm that the child learns to produce with a drum, musical toy, or electric organ.

Behavior. The preoccupation of the deaf-blind child with his or her body produces many problems for the teacher. To bring the child out of the prison of himself or herself requires insight into the use the child makes of his or her sensory apparatus. Sight and hearing are so closely related that when both are even partially impaired, the child seems to rely upon the senses of touch, taste, smell, proprioception, and equilibrium. Touch and smell appear to be closely related to emotions, and prolonged touching is pleasurable stimulation rather than exploratory behavior to learn through touch. Man-

nerisms such as rocking or stroboscopic movements of the hands are also a means of autostimulation.

The staff at San Rafael has noted two groups of deaf-blind children: (1) those who are body-centered because of defective distance senses; and (2) those who stimulate themselves because of neurological damage or dysfunction. The second group is often severely mentally retarded. The behaviors of the two groups are similar in early childhood. Only through therapy does it become evident which children have the potential for progressing through coactive movement to anticipation, imitative behavior, the beginnings of a stable relationship with their teachers, interaction with the environment, and language.

Communication. The school achieved world fame during recent decades because of the system of oral language developed by Father A. van Uden and described in his book, *A Maternal Reflective Method*. The book describes how early conversation between a child and an adult can be helpful to the child if the adult receiving some body or vocal expression from the child interprets to the child what he or she has indicated or said and then gives his or her own response (van Uden, 1968). Provided with a well-planned series of experiences and a few carefully chosen materials, the child can gradually find meaning in a world of objects, time, and space. Too much stimulation results in the child's withdrawal. Insight into each child's capacity for leaving his or her shell as he or she interacts with the external world is a valuable teaching tool (van Uden, 1974).

At San Rafael, language is approached from many sides. Activities are combined with oral sounds, and the Tadoma method is supported by natural gestures. Activities that the child likes, such as water play or eating, are used as reasons for communication through drawings by the child and teacher and serve as bases for reinforcing short-term memory and anticipatory behavior. Finger-spelling is used with some children to back up concepts introduced by oral language (van Dijk, not dated).

An extensive program of preschool counseling for parents makes it possible to begin motor activities, behavioral patterns, and communication skills during the important preschool years.

Grouping. Grouping in a deaf-blind section is important and very difficult. A single teacher per child is undesirable because the child becomes dependent upon that individual in many ways.

The school at Sint Michielsgestel has about 500 children, one fourth of whom are multihandi-

capped: neurologically impaired, socially maladjusted, autistic, mentally retarded, motorically handicapped, aphasic, and deaf-blind. On occasion children may be grouped according to functional level in various activities. For example, some deaf-blind children have taken classes with the normal deaf in language, history, and arithmetic. Some autistic children have been in swimming classes with motorically handicapped. Often children are grouped according to personality characteristics, social needs, and language usage. Many combinations are possible. Placing a deaf-blind child with severely retarded deaf children is less effective than placing him or her with deaf children who have language disorders. The staff believes that routine and familiarity for the deaf-blind are important; however, changes in associates from time to time enable the children to develop the flexibility that will be necessary when they leave the school environment.

In group work, instruction can concentrate upon the capabilities of each child, whereas individual instruction is usually directed toward his or her weaknesses. Both approaches to education are necessary.

Bridges to adult life. Adolescents may be at any level of cognitive functioning, but their bodies change in a pattern similar to that of nonhandicapped children. San Rafael offers sex education in accordance with the means of communication for each child; sports such as swimming, bicycling, horseback riding, or gymnastics; and vocational training. General technical education for the deaf is usually meant for the slow learning deaf child, and deaf-blind children may often be included. They are given a broad base of elementary technical information which helps prepare them to work in five general types of jobs: woodwork, metalwork, painting (houses or furniture), printing, and food distribution (bakery or snack bar). Good working habits, speed and economy in using tools, group cooperation, and the ability to accept, read, or give directions are aspects of vocational training.

After having received adequate preparation, some deaf-blind young people have been placed in ordinary workshops for the sighted on a half-time basis as young as fourteen years of age while continuing their education for several more years. Others in prevocational training eventually go to a sheltered workshop on another campus, which is under the supervision of the Instituut voor Doven. After as many as five years of such experience, they may be placed in sheltered or normal workshops in communities near their homes. More

capable young people move to specialized technical schools after their elementary technical training and enter a broader variety of jobs.

The national coordinator of services for deaf-blind adults was formerly a social worker for the deaf. She had a case load of 384 deaf-blind adults. Many of these were deaf persons who later lost their sight. Approximately 10 percent of the school population at the Instituut voor Doven are known to have retinitis pigmentosa, and planning for their futures is one preoccupation of the school staff.

Because of the school's dedication to learning and the success of their program, the deaf-blind department began to receive many requests from other countries for guidance in their own programs. The Paris office of the American Foundation for Overseas Blind arranged, in cooperation with the department, three short courses for teachers of deaf-blind children from other countries in 1968, 1969, and 1972. The Instituut offered two more courses on its own initiative in 1973 and 1975. While six Europeans have taken the Perkins deaf-blind course, each Dutch course has had from 12 to 20 participants who spend from six to nine weeks listening to formal lectures, watching demonstrations, discussing, reading, and viewing films and videotapes of classroom activities. They have come mostly from European countries; a few have come from the United States, Australia, South Africa, and Tanzania.

The positive results of the courses are evident. The majority of the European programs developing in the 1960s and 1970s adopted large parts of the philosophy and procedures of the Dutch courses.

Invitations were extended to members of the staff at Sint Michielsgestel to come for one to four weeks to institutions in other countries and give specific help with local problems. Participants of former courses sometimes returned for a second course or for parts of second and third courses. Exchange visits lasting from one to six weeks were arranged among former participants of the courses.

The Dutch staff, feeling a great sense of responsibility, increased its efforts to study its own programs and to conduct research with direct practical value.

Scandinavians held several short workshops among themselves, more to look at somewhat different approaches than to try to reproduce the Dutch methods, and their efforts had their own effect upon the Dutch research.

The Italian school held two workshops for its staff taught by Dutch personnel. The new director

spent six months at the Dutch school, and the entire Italian staff visited several times.

It is entirely possible that the sharing of information and the exchange of personnel might have taken place in Europe without the leadership of the Dutch school—leadership not sought but practically thrust upon them. The large numbers of rubella children forced educators to look elsewhere for ideas since the literature was evidently behind the practice in the field. What is amazing is that the relationship among all the programs in Europe is extremely cordial, and none appears to be competing for prominence. There is only pleasure in the sharing, relief at knowing about the struggles others have with similar problems, and keen interest in one another's successes.

Other European Programs

In the two years before World War II, the Instituut for the Blind at Laski, Poland, had begun the education of two deaf-blind girls. In 1953 fourteen-year-old Krystyna Hurszkiewicz was accepted and provided with a full-time instructor, an assistant, and the part-time services of several other teachers. Despite her late entry, Krystyna was able to make some progress in language and concept development, and her teacher published some of her detailed records. Now, at nearly forty years of age, Krystyna spends part of her days with her parents and part at the Institute (Jeziarska, 1963).

At present the Instituut is providing supportive services to a twenty-one-year-old deaf-blind man who is attending a secondary school with sighted students.

A Yugoslav program was begun in 1956 by Petar Vukas at the Veljko Ramadanovic Institution for Visually Impaired Children at Zemun. During the following nine years, three children were accepted in the age range of six to eight years. Now, as adults, two of them are employed by a sheltered workshop in Belgrade, but they work at home. At present Yugoslavia has no known deaf-blind children.

Services in Iceland have been provided to a few deaf-blind children in Reykjavik under the leadership of B. Viglunsdottir, but little is known about any current program.

In Romania writings of a very capable deaf-blind adolescent have been circulated, and the country apparently has a program for a few other children as well.

International Conferences on Deaf-Blind Children

Five world conferences on the education of deaf-blind children have been held. The first, in 1962 at Condover Hall in England, attracted 18 overseas participants and 23 from Great Britain. At each succeeding conference—Denmark (1965), the Netherlands (1968), the United States (1971), and England (1974)—the number of participants increased. Australia will host the 1976 world conference.

In addition to these world conferences, one European regional conference was held in France in 1969.

The value of such gatherings is in the additional stimulation and learning which are possible through international exchange of ideas on a subject about which literature has been comparatively scarce. (A list of conference reports is presented at the end of this paper.)

Summary

Outside the United States programs for deaf-blind children are provided in several European countries, Australia, South Africa, Canada, and Argentina, and instruction for one or two children is provided in Laos, Japan, Singapore, and India. This paper describes briefly the services provided in 13 European countries. Small programs in four others are mentioned.

Of the 350 deaf-blind children in school early in 1975, 101 were in Great Britain, 53 in the German Federal Republic, and 51 in the U.S.S.R. The numbers of pupils in the other countries ranged from 4 to 26. Settings include schools for the deaf in five countries, isolated schools for only deaf-blind in four countries, plus schools for the blind, the physically handicapped, multihandicapped deaf or blind, and even schools for the normal. Great Britain offers the greatest variety of settings.

Three broad bases of instruction are those occurring in the U.S.S.R. where the large proportion of classic deaf-blind permits the inclusion of much subject matter, in Great Britain where a particular sign language is used, and in the countries where the philosophy of the Dutch school has been influential. The Scandinavian countries, while sending representatives to international training courses in the Netherlands, have held their own workshops and meetings.

Much exchange of teachers has taken place among all the countries in western Europe, and four of the five world conferences on deaf-blind children have been held there.

Services extend from early preschool years through young adulthood in all countries. Integration into other groups of handicapped children and into the communities near the school programs has been successful in most countries. Past and present research is mainly concerned with assessment and program development.

European Programs for Deaf-Blind Children

Denmark

Statens Tunghore og Doveskole
Kollengievej, 1
9000 Aalborg

Finland

Jyvaskylan Kunlovikaistenkoulu
Haukkala
40740 Jyvaskyla 74

France

Institution pour Sourdes et Sourds-Aveugles
Notre Dame de Larnay
86000 Biard - Poitiers

East Germany

Oberlinhaus
Rudolf-Breitscheid Str. 24
1502 Potsdam-Babelsberg

West Germany

Deutsches Taubblindenzentrum
Staatlich Anerkannte private Schule
für Taubblinde
Albert-Schweitzer-Hof. 27
3 Hanover-Kirchrode

Iceland

Deaf-Blind Unit
Heyrnleysingjaskolan
Stakkholt 3
Reykjavik

Italy

Instituto Medico Psico Pedagogico
"Nostra Casa"
Via Montecerno, 1
60027 Osimo (Ancona)

The Netherlands

San Rafael Pavilion
Instituut voor Doven
Sint Michielsgestel

Norway

Hjemmet for Dove
Barneavdelingen
3120 Andebu

Poland

Zaklad dla Niewidomych
05-891-Laski-Warsaw

Spain

"Inmaculada Concepcion"
Paseo de la Habana, 208
Madrid 16

Sweden

Ekeskolan
Spec. Skola für Synskadade
Box 9025
700 09 Örebro 9

Switzerland

Aussenstation
Institut Sonnenberg
Pletscha, 17
1700 Fribourg
Beratungsstelle für Taubblinde
Wibbchstrasse, 94
8037 Zürich

United Kingdom

Pathways
Condover Hall School for Blind Children
with Other Handicaps
Condover
Shrewsbury, Shropshire SY5 7AH

Lea Hospital
Blind/Deaf Unit
Stourbridge Road
Bromsgrove B61 OAX Worcestershire

Deaf/Blind Unit
Royal Victoria School for Blind Children
Benwell Lane
Newcastle-on-Tyne
Northumberland NE 15 6SR

Overley Hall
Overley
Telford, Shropshire

Elmete Hall
Elmete Lane
Leeds, Yorkshire LS8 2LJ

Deaf/Blind Unit
Paddock Junior School
9 Spencer Park
London SW18 2SX

U.S.S.R.

National School for the Deaf-Blind
Zagorsk

Conference Reports

Conference on Children with a Combined Visual and Auditory Handicap. Edited by Peggy Freeman. Pembroke College, Oxford: English Deaf/Blind and Rubella Children's Association, 1961.
Deaf-Blind Children and Their Education. Proceedings of the International Conference on the Education of Deaf-Blind Children at Sint Michielsgestel, August, 1968. The Netherlands: Rotterdam University Press, 1971.

Fourth International Conference on Deaf-Blind Children. Report of proceedings, August, 1971. Watertown, Mass.: Perkins School for the Blind, 1971.

Report on Second Conference on Children with a Combined Visual and Auditory Handicap. Edited by Peggy Freeman. Pembroke College, Oxford: English Deaf/Blind and Rubella Children's Association, 1966.

Teaching Deaf-Blind Children. Report of a seminar on the teaching of deaf-blind children at Condover Hall, Great Britain, July 1962. London: Royal National Institute for the Blind, 1962.

Teaching Deaf-Blind Children. Report of a seminar on the teaching of deaf-blind children at Kalundborg, Denmark, July, 1965. London: Royal National Institute for the Blind, 1965.

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Table 1
Historical Development of Services for the Deaf-Blind in Europe

Year	Type of school						
	Deaf	Blind	Physically handicapped	Multihandicapped deaf	Multihandicapped blind	Deaf-blind	Ordinary
1920		Spain					
1938		Poland					
1952		Overley, England			Condovery, England		
1955			East Germany				
1956		Yugoslavia					
1961	The Netherlands						
1962	Finland			Norway		Russia	
1963						West Germany	
1965	Denmark				Sweden		London, England
1966					Bromsgrove, England		
1967						Italy	
1968	France					Zürich, Switzerland	
1969						Fribourg, Switzerland	
1970		Newcastle-on Tyne, England					
1974							9 units Greater London
1975		Leeds, England					
1976		Glasgow, Scotland					

Table 2
Financial Support of Services for the Deaf-Blind

Country	National government	Local government	Church	Private organizations
Great Britain				
London		Partly		Partly
Condoover	Partly	Partly		Partly
Bromsgrove	Partly	Partly		
Overley	Partly	Partly		Partly
Newcastle-on-Tyne	Partly	Partly		
German Federal Republic		Partly		Partly
U.S.S.R.	*			
Italy	Partly	Partly		Partly
Netherlands	Partly		Partly	Partly
France	*			
Switzerland				
Fribourg	Partly	Partly		
Zurich	Partly	Partly		Partly
Sweden	*			
Denmark	*			
German Democratic Republic			*	
Norway	Partly	Partly		Partly
Spain				*
Finland	*			

Table 3
Distribution of Deaf-Blind Children
in European School Programs

Country	Number of deaf-blind children in school	General description			General population of country
		Classi- cal	Rubella	Other	
Great Britain	101	2	61	38	56,000,000
London	(30)				
Condoover	(27)				
Bromsgrove	(25)				
Overley	(11)				
Newcastle-on-Tyne	(8)				
German Federal Republic	53	0	24	29	59,500,000
U.S.S.R.	51	38	4	9	247,000,000
Italy	26	2	12	12	54,000,000
Netherlands	25	—	9	16	13,000,000
France	25	7	14	4	52,000,000
Switzerland	18	2	11	5	6,500,000
Fribourg	(10)				
Zurich	(8)				
Sweden	14	—	13	1	8,000,000
Denmark	11	—	10	1	5,000,000
German Democratic Republic	9	2	—	7	17,000,000
Norway	7	—	3	4	4,000,000
Spain	6	6	—	—	34,500,000
Finland	4	—	3	1	5,000,000
Total	350	59	164	127	

Table 4
Ages of Persons Served
by Programs for the Deaf-Blind

Country	Ages in years								Totals
	-3	3-5	6-8	9-11	12-14	15-17	18-20	Older	
Great Britain									
Bromsgrove		1	8	14	2				25
Overley		3	4	4					11
Condover			3	12	10	2			27
Newcastle-on-Tyne			4	1	3				8
Paddock-London	1		3	3					7
German Federal Republic		5	19	13	3	5	8		53
Italy			5	10	3	7	1		26
Netherlands		1	3	7	3	4	6	1	25
France			4	7	7	3	1	3	25
Switzerland									
Fribourg		1	1	1	4	1	2		10
Zurich		1	1	1	1	2	2		8
Sweden		5	1	3	2	3			14
Denmark		2		7	2				11
German Democratic Republic			2	2		4	1		9
Norway			4	1	1	1			7
Spain			1		1	1	2	1	6
Finland			1	1		2			4
Totals	1	19	64	87	42	35	23	5	276

Primary and Secondary Prevention of Deaf-Blindness

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In this paper, prevention of deaf-blindness will be viewed from two perspectives. The first is primary prevention. This includes those steps that can be taken to prevent a particular cause (etiology) of deaf-blindness. The means with which to prevent some diseases are already available, and their effectiveness is frequently a matter of diligence with which they are utilized. The causes of other diseases are obscure, and no means of prevention are yet known.

Secondary prevention includes those steps that can be taken to mitigate the effects of functional impairment resulting from deaf-blindness. In the consideration of secondary prevention, mention will be made of those areas in which medical intervention may play a role in management.

Clearly, treatment of deaf-blind children is a complex effort requiring the services of a variety of specialists. Each specialist must provide the form of treatment that is standard and appropriate for that discipline. However, the coordination of numerous services and medical specialists is a difficult task that requires the efforts of one primary person, often the pediatrician, to enable one to understand the system of priorities suggested by the consultants and to guard against fragmentation and duplication of care and needless frustration, expense, and anxiety for the family.

Around the country interest is increasing in developing training programs for pediatricians who are interested in providing a broad range of health and other habilitative services for handicapped children. Those programs that are now training pediatricians in relatively narrow subspecialties such as cardiology, hematology, or allergy should be expanded to provide pediatricians who are specialists in the total care of the handicapped child. The goal would be to have these specialists

serve as primary physicians and consultants to hospital-based clinics, medical school teaching programs, governmental agencies, and other child habilitation programs, such as those serving deaf-blind children. The Handicapped Children's Section at Roosevelt Hospital is one such multidisciplinary health care team, rendering clinical services to approximately 1,800 children throughout the New York metropolitan area. Its major orientation is toward the comprehensive functional and therapeutic needs of the child and his or her family. The basic care unit is a team composed of a pediatrician with special interest in the care of handicapped children, a public health nurse, a social worker, and a special educator. Most problems uncovered in caring for patients are handled by the health care team, with back-up support provided by clinicians representing all major subspecialties at the hospital. Many primary services are delivered at the schools for the handicapped in which the children are enrolled. Under these conditions educators, administrators, and others at the school often become members of this health care team. New health service needs may be identified and new programs may be developed because of the presence of the hospital-based physician at the school. During the past year, for example, those in the unit have recognized the need for, and have developed, a gynecology service for multihandicapped children and adolescents and have provided advisory services in the development of sex education curriculum in the schools. Such collaborative programs have the potential for making a major impact in primary and secondary prevention of diseases and disabilities.

Deaf-blindness is such a cataclysmic event in the life of an individual, and its impact on the family and society is so great, that it is prudent to review

some of the causes of this condition so that appropriate preventive steps can be taken.

No attempt is made to catalog herein all the possible causes of deaf-blindness. Instead, many of the most common and representative conditions are described in three broad categories: prenatal infection, genetic disorders, and postnatally acquired. These areas will be considered with a view toward incidence, clinical characteristics, treatment, and preventive measures.

Congenital Infection

Of the many infectious diseases that pregnant women can contract, few, fortunately, are capable of causing serious damage to the developing fetus. Usually, severity of illness in the mother is no index of potential severity of damage to the fetus. For example, while rubella can be mild or even inapparent in the mother, it can seriously affect the fetus. With few exceptions, one attack of an infectious disease results in permanent immunity, and the chance of recurrence in subsequent pregnancies is small.

In infectious diseases in pregnant women, the infecting agent reaches the developing fetus either via the maternal blood stream or directly through the cervix. The injury dealt to the developing tissues through both direct killing of cells and prevention of normal tissue maturation may result in abortion, stillbirth, or a number of serious birth defects, including deafness and blindness.

The following is a description of the most common forms of congenital infection that can result in deaf-blindness.

Rubella

The tragic epidemic of rubella in 1964-65 in the U.S. left hundreds of deaf-blind children in its wake and was, in large measure, the major impetus for the creation of the regional deaf-blind centers. In 1974-75, of the 73 deaf-blind children enrolled at the New York Institute for the Education of the Blind, the largest educational program serving the Mid-Atlantic, North, and Caribbean regional centers for deaf-blind children, 55 were diagnosed as having congenital rubella.

Data derived from the longitudinal follow-up of the rubella project patients with congenital rubella indicate that the period of vulnerability of the fetus to infection with the rubella virus seems to extend from the time of conception to approximately the seventeenth week of gestation. Beyond this point, the fetus seems to be safe from infection by rubella virus and consequent birth defects.

During the period of infection, rubella virus may be found growing in virtually every tissue of the fetus, including that of the heart, eye, inner ear, and brain. It is this pathological process of interaction between the rubella virus and host tissue that results in the constellation of abnormalities that has been called congenital rubella syndrome. The most common specific clinical abnormalities include sensorineural deafness (bilateral or unilateral, mild to profound); congenital heart disease (patent ductus arteriosus or pulmonic stenosis, or both); cataract (unilateral or bilateral), glaucoma, rubella retinopathy, or high myopia; and rubella meningoencephalitis, with resultant degrees of psychomotor retardation with intellectual or motor impairment, various behavioral abnormalities (often autistic in quality), central language impairment, or typical spastic cerebral palsy.

Clinical manifestations and treatment. For a review of the clinical manifestations and management of children with congenital rubella, see the article by Louis Z. Cooper and others (1969), which is included in the references at the conclusion of this paper.

Primary prevention. A primary preventive measure for congenital rubella has been available since 1969, when the use of live attenuated rubella virus vaccine was authorized. Its use is predicated on the belief that a single attack of rubella will confer lifelong immunity. Since then approximately 60 million doses of rubella vaccine have been administered in this country, largely to young children, with the expectation that widespread epidemics of rubella, such as occurred in 1964-65, could be prevented. As anticipated, no large-scale epidemics of rubella in young children have occurred, but there have been local outbreaks in older children and young adults who have not had the disease or who have not been vaccinated against it. Of great importance, therefore, is the screening of women of child-bearing age to determine their susceptibility to rubella. The Rubella HI Antibody test can be used for such screening. This simple blood test is reliable and inexpensive; and, in most cases, results can be made available in 24 hours. The surveys taken at the Roosevelt Hospital in New York indicate that 15-20 percent of the women of child-bearing age in New York City are susceptible to rubella and could be protected with an inoculation of rubella vaccine. However, caution must be exercised in the use of this vaccine; women receiving it must not become pregnant within two to three months following vaccination

because of the potential hazard of exposing the fetus to this attenuated live rubella vaccine virus.

Gamma globulin, a serum fraction prepared from human plasma, has often been given to pregnant women exposed to rubella in an effort to prevent the disease. Unfortunately, as it is generally used, this treatment has not been found effective in preventing rubella infection in the fetus. A special form of gamma globulin prepared from persons convalescing from rubella (rubella immune globulin) is presently under study, with the hope that its use might either prevent congenital infection or render its effects less harmful. It could be used in situations in which the parents will not consider interruption of the pregnancy as an option. At the present time, there is no known treatment that can clear the fetus of rubella infection once the infection has begun. In many cases in which maternal rubella has been documented, the decision is made to terminate the pregnancy through abortion.

Secondary prevention. The deaf-blind child with congenital rubella requires a well-coordinated effort by a large team of clinical specialists to obtain optimal therapeutic results in an educational-habilitative program. Sophisticated treatment by an ophthalmologist, audiologist, cardiologist, psychologist, and others must be carefully planned in advance and must be an ongoing integrated process.

Congenital Toxoplasmosis

Toxoplasma gondii is a protozoan parasite that has been isolated from raw meat with varying degrees of regularity. Ingestion of raw meat by humans or exposure to contaminated litter of cats that have eaten raw meat can establish a widespread infection in a susceptible individual. This disease may be manifest in a spectrum from severe clinical illness to asymptomatic infection. In the pregnant woman, these parasites may gain access to the circulatory system during an infection, cross the placenta, and set up a widespread infection in the fetus. At birth, the infant may be affected with severe, life-threatening disease or may appear to be perfectly normal, only to manifest symptoms later in childhood or, rarely, in adult life.

Clinical manifestations. In the severe form of the disease, the most common findings are hydrocephaly or microcephaly; destructive inflammation of various parts of one or both eyes (chorio-retinitis); and inflammation of the brain and spinal cord (encephalomyelitis), with resultant deposition

of calcium in the brain, convulsions, or mental retardation. The incidence of this disease has been estimated as approximately one in 1,000, although it may be higher among special high-risk groups such as the indigent population in Alabama (Miller, Seaman, and Remington, 1967; Desmonts, 1975). Infection rates vary tremendously from country to country. The highest incidence among western countries in which studies have been made has been in France, where minimal cooking of certain meats, especially lamb, provides early exposure to the parasite.

Treatment. Prompt antimicrobial therapy with sulfonamide antibiotics is generally recommended for infants diagnosed as having congenital toxoplasmosis. Such treatment cannot reverse the damage already done, but it may prevent further injury to the patient.

Primary prevention. No vaccine is currently available to prevent infection by toxoplasma. Research to discover such a vaccine, however, is currently being conducted. The best preventive measures that can be taken at the present time include eating meat only if it is well-cooked and avoiding exposure to contaminated cat feces in litter or sandboxes.

Secondary prevention. As with other congenital infections, early diagnosis of toxoplasmosis and referral to a comprehensive health and habilitation facility are mandatory. Ongoing studies of multi-handicapped children clearly indicate that intervention at birth and during early infancy, through treatment of the underlying disorder and habilitative measures directed at deafness and blindness, can have positive long-term consequences for the child and his or her family. Investigations currently underway to identify children with congenital infection at birth and during early infancy, such as routine screening for elevated IgM levels in the umbilical cord blood, should make important contributions in this area.

Congenital Cytomegalovirus Infection

Fetal infection with cytomegalovirus may be the most common of the congenital infections, with approximately one in 100 consecutive newborns in one series found to be shedding this virus in the urine. As with the other infections previously described, the spectrum of clinical illness in the newborn ranges from severe illness to subclinical infection. However, unlike most of the others described, asymptomatic infection of the mother is

most common; and congenital infection in subsequent pregnancies, although rare, has been reported.

Clinical manifestations. The most severe clinical features of this disease include microcephaly, with meningoencephalitis and calcifications in the brain; chorioretinitis, which may involve one or both eyes; sensorineural hearing loss; and psychomotor retardation (Hanshaw, 1975).

Treatment. No reliable form of treatment has been found for this disease in the newborn or older child, since much of the damage is done in utero and is irreversible. Also, since there may be no rash (as there is with rubella) or other clinical illness during the pregnancy, the congenital infection may not be diagnosed until some time after the birth of the handicapped child.

Primary prevention. No vaccine is available in the United States to prevent congenital cytomegalovirus infection. An experimental vaccine is now being tested in Europe, however. Should that vaccine prove successful, it certainly will be evaluated in the United States.

Congenital Syphilis

Syphilis is a venereally transmitted disease caused by the organism *treponema pallidum*. This organism is able to traverse the placenta after the eighteenth week of pregnancy, when the naturally protective layer of cells in the placenta deteriorates. Fetal infection then results in disease that can vary from clinically inapparent to rapidly fatal. Some signs may not appear until early childhood. These signs include inflammation of the eye, which can progress to blindness (interstitial keratitis), and sensorineural hearing loss.

Psychomotor retardation is one of the common manifestations of the early severe form of congenital syphilis (resulting from syphilitic meningitis).

Treatment. Congenital syphilis can be prevented by adequate antimicrobial therapy of the pregnant woman who is identified as having active syphilis prior to the eighteenth week of gestation. Treatment of such patients beyond the eighteenth week can cure the infection in the fetus, but with variable outcome, depending on the extent of damage already done. Newborns and young infants identified as having congenital syphilis must be treated promptly with antibiotics to prevent the many complications of this disease (Harris and Cave, 1965). Corneal transplantation may prove effective in providing useful vision in patients with scarring secondary to interstitial keratitis.

Primary prevention. No vaccine is available for prevention of syphilis. Therefore, careful monitoring of all pregnant women to determine the presence of active syphilis is mandatory so that prompt treatment can be instituted.

Genetic Disorders

Each of the 46 chromosomes in the human cell has been likened to a string of beads. The beads are called genes. These genes are responsible for individual characteristics such as hair color. Each gene has a precise chemical structure, and is situated on the chromosome in its clearly defined place relative to other genes. Serious variation from this pattern can be incompatible with life, with resultant intrauterine death or stillbirth. Other gene defects may be compatible with life but may result in a serious, lifelong handicapping condition. Despite the great potential for abnormalities in children, the vast majority are born without a serious genetic disorder.

Human beings may be affected by a large diverse group of genetically determined disorders that may include deaf-blindness. As a rule, the birth of the first child with such a disorder is not anticipated by the parents or the physicians charged with the care of the family. Primary prevention, therefore, is principally a matter of identifying asymptomatic carriers in the family and providing genetic counseling to the parents of such handicapped children to familiarize them with the probabilities of their bearing affected children in the future. For some of these conditions, laboratory tests can now be performed to identify the parents as carriers even before the birth of the affected child. Tests may also be performed on the mother during pregnancy to determine whether the fetus is destined to be born with a genetic disorder. For the most part, no specific treatment is available to reverse the course of a genetic disorder in a child so affected, although a great deal of exciting new research in genetic engineering is presently in progress. This research is aimed at finding ways to correct genetic defects and to restore the affected individual to a normal state.

Usher's Syndrome

In 1913, C. H. Usher pointed out the hereditary association of deafness with retinitis pigmentosa in a group of 69 patients. Retinitis pigmentosa is a degenerative disease of the retina, progressing from impaired vision in the dark to gradual constriction of peripheral vision to total blindness, usually by the time a person is in his or her twenties or thirties.

Usher's syndrome is inherited as an autosomal recessive characteristic. In this condition, both parents are normal but carry an abnormal gene responsible for pigmentary retinal degeneration with deafness, probably because of the common embryologic origin of this component of the retina and the organ of Corti of the inner ear. Males and females are affected in equal numbers. The risk for recurrence of the disease in subsequent offspring of these parents is one in four, with two in four appearing to be normal but being carriers of the abnormal gene.

The prevalence of Usher's syndrome in the general population is estimated to be three per 100,000. Among high-risk individuals such as the congenitally deaf, it may be as high as five to ten per 100. The frequency of deafness in a population with proven retinitis pigmentosa has been reported in various series from 32.3 percent to 42.4 percent. Usher's syndrome is considered to be one of the leading genetic causes of deaf-blindness among children attending schools for the deaf and schools for the blind (Usher, 1914; Kloepper, 1966).

Clinical manifestations. The clinical manifestations of Usher's syndrome typically include the insidious onset of severe and progressive visual impairment in a congenitally deaf child. Other common manifestations are related to the central nervous system and include a variety of psychiatric disorders, mental retardation, central language impairment, and loss of the sense of smell.

Modern diagnostic techniques have permitted the detection of abnormalities of the retina in persons prior to the appearance of retinal changes that can be detected with the ophthalmoscope. Such techniques, including electrooculography, have also proved somewhat useful in identifying carriers. The suggestion has been made that such techniques be applied to large populations of high risk, such as children attending schools for the deaf, so that children with Usher's syndrome can be identified early and so that an appropriate treatment plan can be designed for them (Vernon, 1969).

Prevention. All treatment modalities such as hormones and vitamins have failed thus far, making primary preventive measures through genetic counseling of the carriers of prime importance.

Tay-Sachs Disease

Occurring principally in Eastern European Ashkenazic Jews, Tay-Sachs disease results from a genetic absence of the enzyme hexosaminidase A,

with the subsequent accumulation of a fatty substance called GM2-gangliosides in the nerve cells of the body.

Clinical manifestations. The child appears normal at birth but shortly thereafter develops a degree of blindness; psychomotor retardation, which generally is evident by six months of age; and an exaggerated response to sounds. With progression of the disease, response to sounds diminishes, convulsive seizures develop, and death usually occurs by two years of age.

Both parents are carriers of the abnormal gene. Males and females are affected in equal numbers, with a risk of one in four that the disease will recur in future offspring of the parents. The incidence of the disease in Ashkenazic Jewish families is one per 1,000 live births.

Primary prevention. No treatment for the affected child is available at the present time, and the only preventive measures available are performing blood tests on high-risk prospective parents to determine whether they have abnormally low levels of the enzyme so that suitable counseling can be provided. Once an affected child is born in the family, subsequent pregnancies can be monitored by means of the technique of amniocentesis. This test can be used to determine whether the fetus has the disease, is a carrier for Tay-Sachs and therefore essentially normal, or is genetically unaffected. Given this information, the parents may then be given the option of whether they wish to continue the pregnancy.

Large-scale screening programs have been established in many urban areas throughout the United States at special centers concerned with identifying carriers of Tay-Sachs disease. Persons so identified can then be given counseling concerning the risk of Tay-Sachs or the availability of services during pregnancy. In addition, an increasing number of gynecologists are making the Tay-Sachs screening tests available to their patients on a routine basis (Schneck, and others, 1970).

Leber's Congenital Amaurosis (Retinal Aplasia)

Leber's congenital amaurosis is a condition of unknown etiology.

Clinical manifestations. The young infant affected by Leber's congenital amaurosis is soon noted to be moderately to severely visually impaired; however, physical examination of the eye will show little or nothing that is abnormal. The disease usually progresses to total blindness by

adolescence, with the gradual appearance of those changes that are typical of retinitis pigmentosa. This condition may also be associated with diffuse brain disease characterized by mental retardation, seizures, and/or deafness. Males and females are affected in equal numbers, and the risk for recurrence of the disease in subsequent offspring is one in four (Dekeban and Carr, 1966).

Primary prevention. No treatment is available to reverse Leber's congenital amaurosis, and no method exists for intrauterine detection of the condition. Prevention consists of genetic counseling of the parents to familiarize them with the probability of recurrence in their family.

Hurler's Syndrome

Hurler's syndrome is caused by the accumulation in all the body tissues of acid mucopolysaccharides, which disrupt and eventually destroy cell function. The genetic basis of the disease lies in the absence of a single enzyme that is normally responsible for removing acid mucopolysaccharides from the cell.

Clinical manifestations. Children with Hurler's syndrome appear to be normal at birth but within the first year of life experience coarsening of their facial appearance, enlargement of the liver and spleen, stiffness of the joints, and clouding of the cornea. Within a few years, the condition progresses to blindness, deafness, mental retardation, short stature, and limitation of movement at the joints. Death generally occurs before ten years of age.

Males and females are affected in equal numbers, and the risk for recurrence in subsequent offspring is one in four. The disease occurs with a frequency of one in 40,000 live births (Leroy and Crocker, 1966).

Primary prevention. No treatment is available to arrest the disease, and no mass screening test is available to identify carriers. Prenatal detection is possible, however, through the use of the technique of amniocentesis after the fourteenth week of gestation. This provides prospective parents with information about whether the fetus is affected or not and helps them to decide whether to continue the pregnancy.

Albinism

A common form of albinism is the result of the genetic absence of the enzyme tyrosinase, which prevents the formation of pigment in pigment-bearing cells of the skin, hair, and eyes.

Clinical manifestations. The result of albinism is severe limitation in visual acuity (usually 20/200 or worse) as well as photophobia and nystagmus. Occasionally, albinism is associated with deafness and other birth defects such as cleft palates.

Males and females are affected in equal numbers, and the risk of recurrence in future offspring among asymptomatic carrier parents is one in four. The incidence of this disease in the general population is one in 40,000 (Witkop, 1971).

Primary prevention. No treatment is available for the affected individual. Genetic counseling should be offered to the parents and siblings to inform them of the probability of recurrence.

Since albinos have an increased susceptibility to skin cancer, treatments should include encouragement to keep their exposure to sunlight to a minimum.

Postnatally Acquired Diseases

Under the heading postnatal-acquired conditions are grouped those conditions that result in deaf-blindness in an individual who otherwise would have been normal. They differ from the previous conditions in that the disease damages a relatively mature individual when the process of organ maturation is far advanced or completed. With the onset of these types of diseases, the physician must be aware of the possibility of long-term residual disability in his or her patient, even if early and appropriate measures are taken. This is in contrast to the two foregoing groups, in which the patient has already been damaged, usually before the physician becomes involved. In many cases, therefore, the opportunities for primary prevention are more numerous in this group. As with many of the conditions previously discussed, the physician is often confronted by profound ethical dilemmas. For example, the use of oxygen to save the life of the premature infant may also leave the patient blind for life. In general, ensuring that the child grows up in a safe, protected, and caring environment and that the child has ready access to high quality medical care may be among the most important preventive measures that can be taken to guard against deaf-blindness for this group of patients.

Retrorenal Fibroplasia

In the period following World War II, oxygen was used liberally in nurseries to treat newborns, especially infants born prematurely, for respiratory disorders. It was not recognized until the mid-1950s that the blood vessels in the eyes of

premature infants are not fully developed and are especially sensitive to oxygen. During that interval thousands of children in the technologically developed areas of the world became blind because of a condition called retrolental fibroplasia (Kinsey, 1956).

Typically, the disease occurred in infants who were born between 26 and 31 weeks of gestation and who weighed 800–1,500 grams. The more mature the child was at birth, the less frequent and less severe the disease.

Rarely will an infant acquire this disease in room air (oxygen concentration of 21 percent). The chief primary preventive measures utilized, in addition to the prevention of prematurity itself, are careful monitoring of the air being given to premature infants to ensure that the oxygen level rises no higher than 40 percent and measuring the oxygen content of the baby's arterial blood to keep it at a safe level. A standard practice in many nursery centers for infants born prematurely is to perform careful ophthalmologic examination of every infant receiving oxygen treatment to detect early signs of oxygen toxicity to the eyes. With increasing sophistication of such centers, many more small premature infants are surviving without serious impairment, in contrast to previous years in which many died or suffered mental retardation and other neurological impairments. Nonetheless, a small number of survivors are left with severe handicaps, including deafness and blindness. Deafness does not seem to result from oxygen toxicity but is generally a result of the complications of prematurity. Another upswing in the number of children with retrolental fibroplasia may be anticipated as such infants receive more intensive medical services and survive this stormy period.

Neoplasms

Some children are referred to programs for the deaf-blind following surgery for brain tumors. Such tumors are frequently highly malignant and lead to death in a matter of months. With the advent of aggressive neurosurgical techniques, radiation therapy, and chemotherapy, more children are surviving the basic disease process but are left with a variety of impairments secondary to the tumor and the required treatments. Adequate management of such children frequently requires the ongoing services of specialists from many medical disciplines, including neurosurgery, pediatrics, and radiotherapy. Endocrinology consultation may be necessary if hormone replacement is required when the child is no longer able to maintain normal hormonal homeostasis.

The cause (or causes) of cancer in children is still unknown, and no primary preventive measure is available. In consideration of secondary prevention, prompt intervention is required. Once the condition is diagnosed, optimal treatment in some cases may lead to cure. Since the course of such conditions is so variable, every effort should be made to provide the child and the family with a full range of health and educational services so that the handicapped child may lead as full and productive a life as possible.

Trauma

Accidents are the leading cause of death in children. Many children who survive severe accidents or parental batterings are left with chronic, nonprogressive damage to the central nervous system (brain and spinal cord) because of the secondary effects of blood loss, shock, or infection. Inadequate blood supply to vital areas of the brain for even a few minutes can lead to irreversible changes, including blindness, hearing loss, central language impairment, and spastic cerebral palsy. Medical treatment may be able to help the child through life-threatening crises, but frequently it cannot reverse any of these pathological processes. Education, training, and physical rehabilitation programs are required for the child to make the most of his or her residual abilities.

Many children are now exposed to an increasing number of environmental hazards, including air and water pollutants, automobile trauma, flammable garments, or leaded paint. Government, through legislation, plays a primary role in guarding the child's right to a safe and protected environment.

Infection

Infection of the central nervous system (meningitis, encephalitis) is another acquired cause of deaf-blindness in children. Deaf-blindness can result either through direct primary injury to the vision and hearing centers of the brain or through secondary effects such as hydrocephalus. Tuberculous meningitis and similar diseases that are caused by certain viruses and bacteria can also lead to deaf-blindness.

Prompt, intensive treatment must be provided as soon as the earliest signs and symptoms are recognized to prevent complications. Where possible, immunization against specific infectious diseases is the best preventive measure. Public health measures, including adequate monitoring of the general population for diseases such as tuberculosis, are principal tools in preventing infectious diseases.

Summary

Deaf-blindness is not a single-disease entity, but a state of multisensory visual and hearing impairment that can result from a wide variety of pathological processes. Such a condition can arise because of faulty genetic control over embryologic development, from serious infection of an otherwise healthy fetus, or from serious injury to the individual after birth from environmental or other agents.

Control of deaf-blindness in the U.S. is largely a matter of providing a suitable environment for the fetus to develop and a safe, protected environment in which the newborn and young child can mature. Increasingly sophisticated tools have been, or are being, developed by medical scientists to prevent the primary causes of this condition. The utilization of those tools is the responsibility of parents, social welfare agencies, and governmental agencies that must assign priorities for their use in anticipation of the social, fiscal, and political impact of such conditions on the child, his or her family, and the rest of society.

The fetus, infant, and young child cannot articulate for themselves their need for safety and protection. In a period of great competition for scarce resources, obtaining adequate funds to prevent chronic disabling conditions in infants and children, handicapped or healthy, is most difficult. For example, during the past year, federal support for rubella vaccine programs has been virtually eliminated. If effective preventive measures are to be implemented, the following minimum needs must be satisfied:

1. Adequate funding must be provided for programs supporting general prenatal care and health services for infants and children.
2. Adequate funding must be provided for research programs dealing with congenital and perinatal infection and with vaccine development and evaluation.
3. Adequate funding must be provided for research programs dealing with genetic disorders and offering genetic counseling.
4. Adequate funding must be provided for training programs for health professionals to deliver such services.
5. Continued vigilance on the part of legislative and judicial bodies must be maintained to ensure that healthy children are not damaged by environmental agents.
6. Communication with, and education of, parents must be improved with regard to the availability of services, and adequate legal

safeguards must be effected to protect those children whose parents are unable or unwilling to provide a protective and nurturing environment.

7. Society in general must recognize that the social, political, and financial impact of these conditions go far beyond the child and his or her family. Priorities must be reordered in order for the value of human services to be restored to a primary position.

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Hearing and the Deaf-Blind Child

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The audiologist's traditional role is that of evaluating the hearing of children and adults, helping to determine the etiology of a hearing disorder through site-of-lesion testing and providing data concerning the need for audiologic rehabilitation, hearing aid selection, and therapeutic intervention in auditory training and speech reading.

Newby (1972) states that audiologists are individuals whose primary interest is in the identification and measurement of hearing loss and the rehabilitation of those with hearing impairments. This definition is quite adequate for audiologists working in medical settings or speech and hearing centers where the diagnosis of a specific disorder or condition is made by one or two medical or nonmedical specialists. However, the range and magnitude of problems manifest in a child with dual sensory impairments are such as to require a cooperative, interdisciplinary team approach.

As one member of an interdisciplinary team, the audiologist finds himself or herself relating to the psychological, nutritional, medical, environmental, educational, dental, and communicative aspects of the child's condition. The audiologist cannot discuss the child's need for amplification or auditory training out of the total context of the other diagnostic assessments, i.e., the status of the child's home, information concerning previous attempts to train or educate the child, or the type and availability of specific training programs available to the child. The audiological report must reflect awareness of the physical, social, and psychological concomitants present in a deaf-blind child.

Psychological Considerations of Hearing Impairment in a Multihandicapped Child

The psychology of deafness, its effects on thought process, its effect on development of

symbolic reasoning, and its effect on personality and social behavior have all been discussed by numerous authorities. A visit to a school for the deaf clearly demonstrates that children whose primary handicap is a hearing impairment respond socially quite like their normal-hearing peers. One can detect an obvious dependence upon visual stimuli, a high degree of gross muscle activity, and a concreteness in their behavior which may characterize them as being slightly different. But they do communicate with each other, using facial expressions and hand signs, moving their lips, and vocalizing. They laugh, cry, play, learn, and generally appear alert and lively.

The devastating effects of a congenital severe hearing loss are not obvious in a young deaf child whose relatively normal social relationships make him or her seem not too handicapped. Only when the child gets older and the effect of his or her hearing impairment on language development, abstract thinking, and academic achievement becomes painfully obvious are all of the ramifications of the hearing handicap realized. As an adult, other psychological conditions such as paranoia and feelings of extreme isolation become evident. The total impact, then, of congenital deafness is seen in early childhood as a communication problem, in young adulthood as an academic problem, and in maturity as a social-psychological handicap. In spite of the debilitating effects of a severe congenital hearing impairment, most educationally deaf children can, with special training, become productive, self-sufficient adults who can achieve a rich and fulfilling life.

Blindness, in a normal-hearing child, does not prevent the child from developing good cognitive skills and academic agility. Its main impact lies in

the psycho-social areas. Selma Fraiberg (1971) states that a large group of blind children are condemned to "something like a sensory void."

[These children] typically appear to have no significant human ties. Language, if present at all, is echolalic. There is no definition of body boundaries, of self and others . . . Many of these children have not achieved mobility. These children constitute approximately one quarter of the population that is defined by 'total blindness from birth,' excluding children with known brain damage (p. 381).

A combination of deafness and blindness is certainly more than just an additive function. The absence of sensory information about environment, parents, and self prevents the occurrence of normal maturational processes; and the effect may be devastating.

Overview of Anatomy and Physiology of Hearing Mechanism

Anatomically, the ear has been divided into the outer, middle, and inner portions. The outer ear consists of the pinna, which is the visible part of the ear, and the external acoustic meatus or canal. The canal is a cylindrical passage about one quarter of an inch in diameter and leads directly to the tympanic membrane (eardrum). Although the pinna is the most prominent feature of the ear, it is the least useful in hearing. Its function in man is to help collect acoustic signals and direct them toward the tympanic membrane. The tympanic membrane is a thin, concave diaphragm which completely separates the ear canal from the middle ear cavity. The membrane is the first in a series of transducers in the ear. The membrane collects acoustic energy and changes it to mechanical form by moving in concert with the compressions and rarefactions of the pressure wave. In the middle ear, three tiny bones occupy a mucous-lined, air-filled cavity. The first of three bones, or ossicles, is attached firmly to the tympanic membrane, while the third ossicle rests in an oval-shaped window leading to the inner ear. The ossicles form a bridge which transmits the movement of the tympanic membrane to the fluids in the inner ear. A tube, called the eustachian tube, running from the floor of the middle ear to the posterior portion of the throat (naso-pharynx) serves to maintain equal air pressure on both sides of the tympanic membrane by opening and closing during swallowing and yawning. (See Fig. 1.)

The outer and middle ear, in combination, form the mechanism responsible for conducting acoustic signals to the inner ear. An anatomic or functional

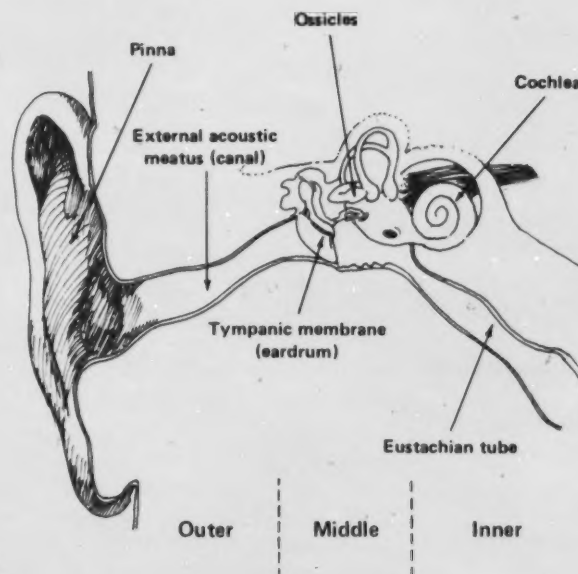


Fig. 1. Diagram of the ear

breakdown of this mechanism that causes a decrease in hearing is called a conductive hearing loss. Impairments of this type are generally sensitivity losses which reduce the intensity of the incoming sound but add little or no signal distortion.

Within the fluids of the inner ear lie the mechanisms which analyze and sharpen the vibratory signal, transduce it into electrical or neural energy, and transmit the information to the eighth cranial nerve, which sends it to both hemispheres of the cerebral cortex by way of a complex neural circuit. The nerve of hearing, the organ of Corti, is a fragile and delicate instrument which is immersed in a fluid and encased in a snail-shaped tunnel in the temporal bone. In spite of its armor-like protective structures, the inner ear is susceptible to numerous insults. The tiny hair cells which respond to pressure waves in the surrounding fluid can be injured by viruses, infections, aging, and numerous other congenital or acquired conditions.

Damage to the inner ear generally results in a more serious impairment than damage to the conducting mechanism. In addition to a decrease in hearing sensitivity, which is usually greater for high frequency sounds than for low frequency sounds, sensory impairments are characterized by pitch and loudness distortion. Furthermore, the filtering effect of hearing some sounds better than others causes the acoustic signal to be even further distorted.

The eighth cranial nerve arising from within the inner ear carries the neural impulses through a bony tunnel to the brain. The neurons proceed to the upper medulla and pons of the brain stem, where most cross over to the contralateral side as they continue up their pathway to the cerebral cortex. A sufficient number of fibers cross back to the ipsilateral side to allow for representation of each ear in both cerebral hemispheres.

Hearing Disorders Generally Associated with Dual Sensory Impairment

The primary etiology of conductive hearing losses in deaf-blind children is otitis media, a middle ear disorder generally associated with upper respiratory infections which cause blockage of the eustachian tube. Otitis media, while common in all populations of young children, is particularly prevalent in handicapped children. The reason for this is not entirely known. A hearing impairment resulting from otitis media generally lies in the slight-to-mild range, causing a reduction in the intensity of incoming sounds. Its presence does not preclude a sensory deficit being present but merely adds to the total impairment. Otitis media, like most conductive impairments, is often amenable to medical or surgical intervention. Many specialists feel that a long-standing otitis media can lead to a permanent hearing loss. For this reason periodic otologic examinations are recommended for all multihandicapped children.

Occasionally, other conductive hearing losses accompanying congenital malformations of the outer or middle ear are found in the deaf-blind population. Richards (1964) found stapedial footplate fixation present in three rubella children. However, Borton and Stark (1970) noted that approximately 75 percent of the rubella children in their study exhibited pure sensorineural impairment.

Because the majority of deaf-blind children are products of maternal rubella, a consideration of the effect of this disease on the hearing of the affected children is important. Histopathologic studies reveal that the inner ear defects due to maternal rubella depend somewhat on the stage of fetal development at the time of the infection as well as the degree of severity of the inflammatory process. Most reports suggest that the degenerative process is limited to the cochlear duct and the structure within it and to the sacculus. The organ of Corti varies in degree of degeneration, but may be fairly well developed with some hair cells recognizable (Lindsay, 1967).

Audiometric findings in rubella children appear to vary as a function of the particular virus strain. Although a majority of the hearing impaired children have severe or profound losses, a number of rubella children demonstrate only mild or moderate hearing deficits. Borton and Stark (1970) reported on the audiometric findings of a large population of rubella children. These investigators found that 40 percent of the hearing impaired children demonstrated better hearing for low frequency sounds than for high frequency sounds. Other audiometric configurations found included saucer-shaped audiograms and flat or rising losses. Saucer-shaped audiograms are not characteristic of sensorineural losses associated with other disease processes.

The presence of central deafness in rubella children has also been suggested by several authors (Levine, 1951; Vernon, 1967). In central deafness the child is unable to utilize incoming signals in a meaningful cognitive manner. Because of this, rubella children in classes for the deaf often present behaviors which suggest that they have a learning disability. They may not learn to lipread as well as expected, may have reading problems or other academic learning difficulties, or may demonstrate reduced memory span. Finally, one must remember that a rubella child may suffer from the combined effects of a middle ear, sensory, or central hearing loss.

Although the largest percent of deaf-blind children are confirmed products of maternal rubella, the population is not limited to that single etiology. A sizeable group of deaf-blind children results from meningitis, prematurity, neonatal ataxia, Rh incompatibility, and other unspecified conditions (Bernstein and Roeser, 1972). A review of the report on deaf-blind children in Michigan reveals that approximately 47 percent were confirmed products of maternal rubella, while nearly one-third of the cases were of unknown etiology (Harris, 1971). These findings make apparent the fact that the effect of mass inoculations for the rubella virus could reduce the number of congenitally deaf-blind children by approximately 50 percent. The vaccine will not, unfortunately, completely eradicate the problem of congenitally deaf-blind children.

Identification of Hearing Disorders in Infants and Young Children

Identification of a hearing impairment in a multihandicapped child can be extremely difficult even for the experienced diagnostician. It might be

well to consider the development of auditory behavior and other developmental milestones in deaf-blind children and to compare the developmental sequelae. That the human cochlea has normal adult function after the twentieth week of gestation has been confirmed physiologically. Normal-hearing neonates, therefore, have been hearing fluid-borne sounds for three to four months prior to their birth. Newborn infants may be awakened by a loud sound and will startle to abrupt presentations of intense acoustic stimuli.

Normal-hearing newborns show the ability to discriminate between various acoustic stimuli, preferring speech-like signals to other sounds. They show predictable behaviors such as eye widening, cessation of activity, sucking changes, and limb movement to various types of auditory sensations. By four to seven months of age they localize sound sources, turning their eyes and head toward the noisemaker or speaker. From six to nine months we see an increase in the infant's vocal play and a utilization of various vocalizations to express pleasure or displeasure with the environment.

For a number of reasons, a normal-hearing infant may not develop auditorally as described. Severely mentally retarded children, children with central nervous system dysfunctions, and severely emotionally impaired children will often fail to respond to auditory stimuli even though their peripheral auditory mechanism is intact. The developmental signs which differentiate multihandicapped deaf children from multihandicapped normal-hearing children are indeed subtle. One can find a wide range of general developmental maturation in a deaf-blind population. Although a delay in gross motor development is characteristic of deaf-blind children, one must be cautioned to consider the possible effect of other problems such as the severity of a heart defect or the child's age when cataract operations were performed (Robbins and Stenquist, 1967). In conclusion, one generally cannot identify a hearing impairment in a multihandicapped child solely by noting the variant developmental responses to auditory stimulation.

High Risk Criteria Relevant to Hearing Loss

Much has been written recently about the importance of early identification of hearing impairment in infants. Relating the findings of studies on sensory deprivation in animals to delay in treatment of visually or auditorally-impaired children has become fashionable. For hearing-impaired children, substantiating such a correlation is difficult, although the argument certainly has a

great deal of face validity. In any case, early identification of a hearing impairment in a multihandicapped child may prevent misdiagnosis as severely mentally retarded, therefore enabling the child to obtain appropriate educational and training opportunities.

A high risk register for identifying a hearing impairment in neonates, that is, a listing of infants with predisposing conditions usually associated with congenital deafness, was suggested by the Joint Committee for Infant Hearing Screening (Cunningham, 1971) and includes the following factors: (1) history of hereditary hearing impairment; (2) rubella or other nonbacterial uterine fetal infection during pregnancy; (3) a defect of ear, nose, or throat; (4) birth weight of less than 1,500 grams; and (5) bilirubin level greater than 200 mg. per 100 ml. of serum. Of these criteria, maternal rubella and familial history of hearing impairment are most frequently found in the hearing-impaired child's history form. All newborns whose birth histories contain high risk factors for hearing impairment should receive audiological follow-up until such time as the absence or presence of a hearing impairment can be unequivocally substantiated.

Application of Hearing Screening Programs to Multisensory-Impaired Infants and Young Children

Mass hearing screening programs for neonates have been advocated by Downs since 1967. Goldstein and Tait (1971) and Ling and others (1970) have since pointed out the shortcomings and dangers of this procedure, as did the Joint Committee for Hearing Screening (Cunningham, 1971). Although Downs reluctantly backed away from her recommendations for mass neonatal screening in favor of a combination high risk register and mass hearing screening, dozens of hospitals presently conduct some form of mass hearing screening of newborns. Since high risk registers contain historical or physical findings preselected for their probability of being related to hearing loss, in nearly every instance the multihandicapped child can be detected by the high risk register described. As stated previously, this author's recommendation is that all children who are high risk for hearing impairment undergo extensive workups.

Preparation for Diagnostic Audiological Evaluation

A complete and carefully recorded case history is a prerequisite to understanding the nature and extent of a child's auditory disorder. Myklebust

(1954) considers differential history-taking as part of the total diagnostic examination. He states that a considerable difference exists between differential history taking and the more routine types of history taking because in differential history taking the diagnostician must be continuously evaluating the information that is obtained. The differential history emphasizes information pertaining to the various etiological categories. A case history for the differential diagnosis of an auditory disorder in multihandicapped children should include the following: (1) The birth history should include information on the mother's pregnancy and duration of labor, as well as the delivery and neonatal course of the child. Additional information should be obtained concerning any unusual appearance or behavior of the newborn, his or her general physical condition, and whether jaundice, anoxia, or other indications of damage were present at the time of birth. (2) The medical and health history should contain information about the child's condition immediately following birth (seizures, scars, bruises or other deformations, feeding difficulties, or swallowing and sucking problems) and the child's later experience with injury, illness, or surgery. (3) Developmental behavior history should include questions such as when the child began to sit alone, when he or she began to respond to parent's voice, stood alone, walked, finger fed, and drank from a cup. Parents should also be queried as to whether or not this child's development was markedly different from that of his or her siblings. (4) The portion relating to the emotional adjustment of the child should contain questions regarding the child's sensitivity to vibratory sensations, visual stimuli, and auditory signals. Queries regarding responsiveness to objects, consistency of behavior, responsiveness to people, distractibility, and hyperactivity should also be made. (5) Auditory history questions should include whether the child responds to any sounds or to loud sounds only, uses his or her hearing projectively, seems to ignore sounds, or shows fear of sounds. Experiences the child has had with amplification should also be noted. In addition, determining whether changes have been observed in the child's response to sound over the years is important. (6) The expressive communication history is extremely important to explore. The child's speech and language development should be searched in depth. The diagnostician should question parents regarding how the child uses his or her voice, his or her rate and pattern of language development, other modes of communication the child has used, and whether the child ever babbled,

used jargon, vocalized for pleasure, or communicated by crying, laughing, or pointing. Finally, the diagnostician should determine whether the child had acquired speech and then stopped talking, never used his or her voice, used echolalic speech, or used vocalizations projectively. (7) The educational history should provide a diagnostician with information regarding the type and nature of educational experiences the child has had. If the child has attended a nursery school or other preschool program, reports from teachers describing specific classroom behaviors can be invaluable.

Prior to formal audiological evaluation of the young, multihandicapped child and following completion of a diagnostic case history, informal observation of the child's responses to environmental stimuli, speech, and noisemakers should be carefully noted. In an unhurried fashion the audiologist carefully observes the child for signs of eye or head movement, postural changes, cessation of activity, laughing or crying, eye blink, or changes in self-stimulatory activity, which may be related to the absence or presence of a particular auditory signal. If possible, the child should be seen with the mother present. The way the child responds to the mother's voice, facial expressions, and movements while sitting on her lap or in a high chair or seat in front of her can provide valuable cues to the observant diagnostician. The child should also be observed while sitting or lying on the floor, quietly playing alone. Background noises used to stimulate behavioral responses may include musical toys, bells or drums, squeaking toys, whispered or spoken voices, rattles, slamming doors, warbled tones, or other calibrated or uncalibrated noisemakers.

Interpretation of the absence or presence of behavioral responses to environmental sounds must be made cautiously. Most deaf-blind children lack curiosity and rarely try to establish communication. Because of this, attributing a greater sensory impairment to multihandicapped children than actually exists is not unusual. Furthermore, an inability to coordinate certain motor activities may mistakenly be interpreted as depressed sensory functioning.

Finally, behavioral observation must include presentations of visual and tactual stimuli. A comparison of how the child responds to bright and dim lights, touch and tickle, and to various intensities and types of auditory stimuli is critical in understanding the nature of the child's total handicap.

Audiological Assessment

Audiologic testing is designed to assess the integrity of the entire auditory mechanism. The standard battery of audiometric tests includes pure tone testing which measures the sensitivity threshold for discrete frequencies of 250 through 8,000 Hz, as well as speech-hearing tests. Audiometers are calibrated so that normal-hearing young adults will obtain thresholds of 0 db for pure tones and for speech. Differences between an individual's particular threshold and the average normal hearing threshold (0 db) for speech or for a given frequency presentation are recorded in decibels of hearing loss. Thus, looking at an audiogram, one can tell whether a person's hearing thresholds are mildly, moderately, or severely reduced relative to average normal hearing. Speech testing routinely includes determination of a speech reception threshold (the lowest level at which an individual can repeat a bisyllabic spondaic word such as baseball or railroad correctly 50 percent of the time) and speech discrimination testing, which theoretically assesses an individual's ability to discriminate between various monosyllabic words. Most speech discrimination tests are designed so that a person with normal hearing or with a conductive loss will achieve scores of nearly 100 percent. Persons with a sensorineural loss will, because of internal signal distortion, generally miss a substantial number of items.

The standard audiometric tests described require a subject to be cooperative and alert and to have a mental age of at least four or five years. Few, if any, deaf-blind children are able to be tested in this way. Even with sufficient motivation and intelligence, these children could not be instructed to respond in a standardized way.

Since the early 1960s, most of the research on clinical audiometric procedures has centered on determination of the site of lesion in a hearing-impaired individual. These tests (SISI, Bekesy, tone decay, loudness balancing, and so forth) require sophisticated audiometric equipment and a highly trained audiologist for administration and interpretation of test results. Most university training programs in audiology spend great time and effort teaching students to be competent in administering routine and specialized tests to cooperative subjects. Unfortunately, few audiologists receive adequate training to permit them to participate meaningfully in the differential diagnosis of hearing impairment in a multihandicapped child. To merely modify the standard test battery slightly

and attempt to apply the basic procedures or to interpret the test results in a traditional way with this population is not sufficient. Speech hearing tests, for example, are not usually applicable to the deaf-blind child. Furthermore, most test instructions are given verbally or in conjunction with gestures which these children may not be able to receive.

The lack of specific information in the literature regarding the application of audiometric tests to a deaf-blind population reflects the state of the art at this time. A relatively few notable clinicians (Bernstein, 1972; Calvert and others, 1972; Litynski, Lewis, and Reddell, 1970) have bravely discussed their experiences with audiometric testing of small groups of deaf-blind children. This author will attempt to collate the reports of these clinicians with the unpublished report of an audiologist who has had extensive clinical experience evaluating deaf-blind children (E. Soper, 1975) and with this author's personal experiences with this population.

Special Diagnostic Procedures with the Difficult-to-Test

The special diagnostic procedures that are used with children who are difficult to test are described here.

Behavioral Observation Audiometry (BOA)

The behavioral observation audiometry procedure is usually reserved for testing infants or difficult-to-test children. The methodology is in many ways similar to that utilized in the observation of a child in an unstructured situation but is more precise in that carefully controlled acoustic stimuli (warbled tones, wide and narrow bands of noise, speech, and so forth) are presented to the child in a controlled environment. Most often the child is seated in a soundproofed room on his or her mother's lap, in a highchair, or on the floor. Periodically, acoustic signals of varying intensities and spectrum are presented. The child's behavioral responses are carefully noted for levels of awareness to low intensity sounds as well as for any signs of being startled by high intensity sounds. As in testing infants, the most frequently noted behavioral response of deaf-blind children to sounds is a cessation of activity. The child, without turning, pauses momentarily in his or her rocking, humming, kicking, or grabbing behavior and then returns to his or her prestimulus level of activity. Most neurologically involved children characteristically demonstrate excessive startle responses to succes-

sive presentations. However, in this author's experience, deaf-blind children exhibit few, if any, sharply defined startle reflexes.

An important aspect of behavioral observation audiometry is the careful notation of the type of response elicited by the auditory stimulus and the response intensity. Because of the high probability that the child's motor activity will accidentally coincide with a stimulus presentation on occasion, responses which cannot be repeatedly obtained at a particular intensity level should be viewed with skepticism. The audiologist can easily see changes in behavior when sounds are presented at intensity levels which the audiologist feels the child can hear. At the University of Michigan Institute for the Study of Mental Retardation and Related Disabilities, we have found that our objectivity is improved considerably when videotapes of the child's behavior during the examination are carefully reviewed. A final important aspect of behavioral observation audiometry is in the determination of an appropriate stimulus intensity level to be used in subsequent audiological conditioning procedures.

Visual Reinforcement Audiometry (VRA)

Visual reinforcement audiometry, a term first coined by Liden and Kankkonen (1961), includes the use of any type of visual stimulus to reinforce a child's localization or searching movements associated with the presentation of an acoustic stimulus. Suzuki and Ogiba (1961) described a formal conditioned orienting response (COR) technique in which the child's orienting toward the sound source was reinforced by flashing a light in a brightly colored toy on top of the audiometer speaker. Most audiologists who work with difficult-to-test children find the COR paradigm too restricting for the numerous behavioral characteristics of handicapped children. However, the use of a visual reinforcer to obtain reliable results with the deaf-blind has proven to be surprisingly effective.

Bernstein and Roeser (1972) found that most of the deaf-blind children in their study had sufficient visual acuity to perceive the light stimulus. They stated that some problems were encountered when children tended to fixate on the light, but they felt that the procedure was successful in 24 of the 34 children above the age of one year. Calvert, and others (1972) also found light to be a strong response reinforcer among the deaf-blind children. To reduce the distracting effect of the ceiling light,

these investigators used a diffused reflector with a dimmer switch, and in the visual reinforcement objects they fitted brighter bulbs or used bare Tensor light bulbs to attract the child. They concluded that, although a number of deaf-blind children with suspected gross central nervous system damage could not be conditioned to visual reinforcement audiometry, the approach was successful with most of the deaf-blind children, and they recommended this technique as one of the procedures to be used in the audiological evaluation.

The successful use of visual reinforcement audiometry by previously reported audiologists confirms the clinical impressions of this author. We have observed that a child with minimal residual hearing and vision will almost always favor visual stimuli over auditory stimuli. Children will tend to seek out intense visual stimuli, will flutter their fingers in front of their eyes and may poke their thumbs or fingers into their eyes in search of sensory stimulation. On the other hand, the child will not generally seek out sources of auditory stimulation, will not usually startle to intense auditory stimulation, and may be indifferent to directionality of an acoustic signal as well as to changes in the signal spectrum. Our clinical experience with deaf-blind children suggests that much information can be gained through the use of visual reinforcement audiometry in approximately one-half of the cases. We generally darken the test room to accentuate the reinforcing light. We, like the other authors, feel that the technique described is more likely to be successful with higher functioning children than with the multihandicapped, severely retarded population.

Tangible Reinforcement Operant Conditioning Audiometry (TROCA)

Tangible reinforcement operant conditioning audiometry, described by Lloyd and others (1968), utilizes positive reinforcement for appropriate responses and a mild punishment (time out) for false-positive responses. The reinforcer is generally an edible substance such as candy or sugar-coated cereal but may also be in the form of a trinket or token. The child learns through a conditioning procedure to press a response button on a feeder box whenever he or she hears a sound. Clinical experience with mentally retarded children has shown this to be a very effective procedure for determining audiometric threshold. Unfortunately, little support for utilization of TROCA with a deaf-blind population can be found.

Although Lloyd and others (1968) suggested combining a visual stimulus (bright light) with the auditory stimulus during the initial conditioning procedure, a dual sensory input is not usually beneficial in conditioning the deaf-blind child. Calvert and others (1972) reported that with most deaf-blind children the light was a stronger primary reinforcer than the food and appeared to be very rewarding to the children. However, most of the children could not be brought under stimulus control for the dual sensory presentation, and few were able to make the transference to an auditory signal alone. When these researchers attempted to condition the children to press a brightly lighted key and then switched the light from one key to another, only a small group of the children achieved responses satisfactory even for determining their threshold for light.

Similar experiences were reported by Litynski and others (1970), who stated:

It is apparent that our population was much more severely involved, especially in sensory areas, than that used by Spradlin and Lloyd, using the TROCA techniques. Spradlin and Lloyd used selection in their subjects and also had a very stable institutional population. It appears that both factors are significant for achieving success with the TROCA approach . . . Over-and-above the procedural difficulties, the severity and complexity of handicapping conditions of the population of this study contributed to the disappointing results of using the TROCA techniques and operant conditioning in general. Their disabilities include sensory areas, which limit input of stimuli; they include the central nervous system, which limits the integration of input information, and they include motor control, which limits the ability to respond. The slow, sporadic response rate, the lack of retention of a simple task over a brief period of time, and the failure to master a simple discrimination task when accompanied by both response feedback and reinforcement all suggest that the central nervous system impairment in these children was massive.

These authors conclude that although they had sought to test hearing acuity, they may have been testing raw potential to learn. The operant conditioning procedures, therefore, could have considerable value with a deaf-blind population in determining potential academic abilities.

The author's experience with TROCA suggests that it is likely to be more effective with older (nine to twelve years) deaf-blind children than younger ones. Finding a suitable reinforcer with deaf-blind children is particularly difficult. Although most of the children will mouth objects frequently, they are not usually good eaters.

Furthermore, few younger deaf-blind children self-feed, and most have difficulty associating the motor act with the subsequent reinforcer. In summary, TROCA with deaf-blind children is not usually successful because of the difficulty in finding a suitable reinforcer, the distractibility of the children, their self-stimulatory activities, and their limited ability to integrate input information.

Conditioned Play Audiometry

The term "conditioned play audiometry" describes any test in which the child is taught a play response to an auditory stimulus. Usually the response is putting a ring on a peg or dropping a block into a box. However, any motor act which the child can be taught to perform on signal and which contains an element of fun or play may be used to assess auditory sensitivity. This procedure, which is routinely used for testing children between the ages of two and five years, has been shown to be extremely effective when the motor act is reinforced by combining successful play activity with praise, hand clapping, and overall excitement on the part of the tester. An enthusiastic audiologist can many times complete air conduction, bone conduction, and speech testing in one session with a young child when these procedures are followed.

Little can be found in the literature on the use of conditioned play audiometry with the deaf-blind. Bernstein (1973) attempted to condition a group of children to a play audiometry paradigm. She found that music proved to be the most successful auditory stimulus. Parents or teachers were taught to work with the children for short sessions each day, associating a motor activity, such as standing up or sitting down, with the absence or presence of sound. Some children required six months to one year of training before audiological testing could be accomplished, and most of the children failed to perform consistently even after many months of intensive training.

The audiology clinicians at the Institute for the Study of Mental Retardation and Related Disabilities, University of Michigan, have found conditioned play audiometry to be ineffective with almost all of the deaf-blind population. Many of the reasons previously cited in reference to limitations of the TROCA technique with the deaf-blind apply to play audiometry: the social reinforcement is not reinforcing, the motor act is not fun for the children, and integration of the stimulus-response paradigm does not readily occur.

Objective Hearing Tests

The development of objective tests of hearing, that is, tests which measure the hearing function by monitoring electrophysiological or other involuntary responses resulting from presentation of acoustic stimuli, has been of great interest to audiologists who work with difficult-to-test children. Unfortunately, most so-called objective hearing tests designed to overcome the problems associated with behavioral tests have serious shortcomings of their own. A brief discussion of these shortcomings should help the reader understand why most clinical facilities do not utilize many of the objective tests touted so enthusiastically in professional journals.

One major problem with objective tests is that a certain degree of passive cooperation is necessary on the part of the subject even though no specific behavioral response is required because a child cannot be tested if he or she is screaming or crying, pulling off wires or electrodes, running around the test room, or punching himself or herself or the tester. Many times, with deaf-blind children, these activities cannot be prevented without the use of a sedative. The use of sedation in children presents two additional concerns: first, a physician must be present for prescribing dosage and monitoring the child during sleep. This factor eliminates nonmedical facilities from performing certain objective tests. Second, many times the drug itself will cause a change in physiologic or electrophysiologic activity, thus obscuring the resultant test data.

Another reason why objective hearing tests have generally proven to be ineffective with multihandicapped children is that these tests are developed on older, cooperative children or on adults. The generalization of results obtained with cooperative subjects to the clinical population does not always follow. Finally, one must be aware that objective tests tend to lose their objectivity when the audiologist attempts to interpret the data. The professional literature contains reports of many studies demonstrating that tester bias as well as shifting standards greatly influence an audiologist's interpretation of physiologic test data. A significant improvement in intratester and intertester reliability in judging responses must be achieved before a specific technique can be considered valid. One further caution is added by Northern and Downs (1974), who state that "we should pause to reflect that the presence of some physiologic response, seemingly related to the presence of an auditory signal, does not ensure that the child does indeed 'hear.' Hearing in this sense implies mean-

ingful interpretation of the sound so as to produce thought and language with verbal or nonverbal encoding and decoding."

Three of the more promising objective procedures are electroacoustic impedance testing, electrocochleography, and electroencephalic audiometry. These procedures are briefly described here.

Electroacoustic Impedance Testing

The electroacoustic impedance test was first described by Metz in 1946 and has recently become an integral part of the standard clinical armamentarium with which audiologists deal. The electroacoustic bridge is designed to evaluate the way in which the middle ear conducts sound waves to the inner ear. By comparing how much sound the eardrum absorbs relative to how much sound it reflects back out the canal, the instrument can specify the amount of stiffness in the system. In addition, the bridge is capable of detecting changes in impedance associated with middle ear muscle activity. Since this muscle activity is related to the loudness with which a person hears a sound, much information about a child's ability to hear and the status of his or her middle ear mechanism can be readily obtained.

The impedance-measuring instrumentation is relatively inexpensive and can be operated by a trained technician. Furthermore, only a few minutes are required to administer the tests to each ear. Although subjects are only required to sit quietly during administration of impedance tests, many deaf-blind children will not tolerate the probe in the ear and thus cannot be adequately tested. In spite of this limitation, impedance testing has proven to be quite beneficial with many deaf-blind children and should be used whenever possible. The reader should note, however, that because specific pure tone thresholds cannot be determined by impedance testing, the information derived can rarely be used alone. The information is best used to confirm or supplement other data.

Electrocochleography

Electrocochleography has recently gained international interest. Investigators in France, Israel, and Japan, as well as the United States, have all reported success with this procedure. The successful laboratory utilization of electrocochleography has resulted mainly from refinement of sophisticated electronic instrumentation. This technique, which measures electrical activity of the inner ear and the eighth cranial nerve by putting a needle electrode into the external auditory canal,

or through the eardrum to the promontory, seems to hold great promise for the future. Unfortunately, because of the sophisticated, delicate electronic instrumentation required and the need for sedating the child, as well as the need for medical surveillance, this technique is impractical as a clinical tool at this time. Furthermore, since it measures auditory reception rather than central auditory processing, test results must be interpreted cautiously. This procedure will possibly become a clinical tool in the future but for now it remains an exciting research technique.

Electroencephalic Response Audiometry

Much has been written about electroencephalic response audiometry, which measures changes in brain wave activity associated with auditory stimulation. Although scientists have known for many years that changes in brain wave activity occur in conjunction with an auditory stimulus, rapid identification of these changes could not be made easily. With the advent of inexpensive signal averaging computers, investigators all over the world began reporting successful utilization of the technique to assess hearing thresholds. Instead of merely looking at electrical brain wave activity associated with one acoustic stimulus, electroencephalic audiometry averages the brain wave activity of repeated presentations at the same level, thus reducing random electrical activity.

Although many of the limitations of electrocochleography are also present with electroencephalic audiometry (i.e., expensive, sophisticated electronic equipment, need for sedation of the subject in many cases, and difficulty of interpretation), the procedure has gained wide acceptance as a research tool and scattered support for clinical utilization. Electroencephalic audiometry has been shown to be a valid, reliable procedure for cooperative adults. Sadly, though, its greatest weakness is in the detection of hearing sensitivity in the mentally retarded, neurologically impaired, and multihandicapped, the very ones in whom the procedure would be most valuable (Northern and Downs, 1974). Since research in this area is being carried out by numerous laboratories and clinics, a breakthrough will probably occur in the next few years which will allow for examination of the multihandicapped child through electroencephalic audiometry.

Hearing Aids for the Deaf-Blind Child

Few deaf-blind children are totally deaf. This is especially true among rubella children, in

whom total deafness is extremely rare. A general principle in working with hearing handicapped children is that the earlier amplification can be started, the more likely the child is to learn to use his or her residual hearing for language development. Although it has not been conclusively demonstrated, a general consensus among educators of the deaf is that early sensory deprivation in a child greatly decreases future use of sensory information received through the defective modality. Some authorities speak of a critical period in which it is necessary for the hearing-impaired child to receive language input in order to avoid severe language retardation. This theory is that the reception and utilization of particular types of stimuli are optimal during certain periods in a child's development. Subsequent stimuli will have gradually diminishing potency in effecting the child's development in the function represented (Northern and Downs, 1974).

Whether or not the concept of a critical period is valid, a multisensory-impaired child will apparently suffer extreme deficits in all areas of social, psychological, and cognitive development as a result of a lack of external sensory stimuli. It is difficult to believe that amplification of incoming sensory stimuli, whether they are auditory or visual, would not be beneficial to these children. In spite of this seemingly obvious conclusion, the fact is that a large percentage of deaf-blind children are not fitted with amplification until they are five or six years old and many do not wear the hearing aids which have been purchased for them. The reasons for this are interesting. One obvious reason has been previously discussed: the diagnosis of deafness in a multihandicapped child is profoundly frustrating and difficult to make. Most audiologists are loathe to make a recommendation for hearing aids in a child for whom a clear-cut diagnosis is not possible. Even though the potentially devastating effects of not putting a hearing aid on a child with a hearing loss are perhaps greater than the effects of putting a hearing aid on a normal hearing child, audiologists will usually be quite conservative in their judgments and err in the direction of withholding amplification from a child with an uncertain diagnosis.

Another reason for delay in procuring hearing aids for deaf-blind children is that other physical conditions (e.g., heart problems, nutrition problems, orthopedic problems, and severe developmental retardation) often overshadow any concerns regarding the status of the child's hearing. In addition, many audiologists are reluctant to recom-

mend amplification for a very low functioning child because he or she will probably be unable to process incoming signals in a meaningful way. These arguments are strong, and the present author has used them all at various times. In retrospect, however, withholding amplification from a deaf-blind child because of any of the above mentioned reasons is extremely difficult to justify.

Types of Hearing Aids

Hearing aids are generally classified as either body borne or ear level. Body-borne aids are worn in a halter on the chest. The body instrument is attached by wire to the receiver. An earmold is fastened to the receiver and placed in the ear. Body-borne aids can be quite powerful. They have greater flexibility in terms of frequency response and other acoustic alterations and are usually sturdier than ear-level aids. The protective outer cases, large dials and switches, and sheer bulk make body-borne aids desirable for the younger child who is likely to treat the instrument roughly and carelessly.

Ear-level hearing aids are generally small, encased in plastic, and lightweight. They sometimes are designed to fit in the external ear, but most hang behind the pinna. As a rule, ear-level aids have an internal receiver and send the amplified sound to the ear via a clear plastic tube attached to the earmold.

Adults who have a mild, moderate, or even moderately severe hearing impairment usually prefer ear-level aids because of the reduction of clothing noise and the naturalness of sound directed to the head. For infants and young children with moderate or severe hearing impairments, body-borne aids are almost always the choice, since an ear-level aid would be quite impractical with this age group.

Hearing aids may be worn singly (monaural), one hearing aid for each ear (binaural), or one hearing aid sending the same signal to both ears (pseudobinaural). Once again, hard evidence regarding the benefits of true binaural versus pseudobinaural hearing aids is lacking. However, many teachers of young deaf children state that children fitted with binaural hearing aids do better than those with monaural or pseudobinaural fittings. To be consistent with a policy of providing as much sensory input as possible to sensory deprived children, one cannot in clear conscience recommend less than true binaural hearing aids for the deaf-blind child. Because of the many problems involved in getting a child to accept and utilize

amplification, one would probably be wise to utilize initially a single hearing aid, alternated weekly between ears, until such time as the child has accepted the instrument.

Problems in Getting Deaf-Blind Children to Accept Amplification

Parents of hearing-impaired children often report a reluctance on the part of the child to accept amplification. The children do not like its physical presence, the loud unpleasant sounds coming from it, or the earmold sitting heavily in the pinna. However, with patience, firmness, and determination, parents can, within a few weeks, usually secure the cooperation of the child in wearing the instrument. As soon as the child realizes that he or she is missing something without the aid, the need for parental coercion disappears. This is not so with the deaf-blind child. The deaf-blind child seems to be particularly bothered by intrusion from the outside world, and any attempt to attach a hearing aid to his or her body is met with great resistance. He or she will pull the earmold from the ear, chew on the connecting wires, and angrily attempt to smash the hearing aid itself. Also, amplified sound from the hearing aid may cause him or her to react violently. His or her behavior many times will suggest that the sound is painful. When this occurs, parents and teachers question the appropriateness of the hearing aid and therefore may not insist upon its usage. Furthermore, even with amplification, the deaf-blind child may not respond to speech or noise differently than he or she did when he or she was not wearing the aid. This behavior tends to reinforce the parent's or teacher's impression that the hearing aid is not helping the child.

An important factor which inhibits proper hearing aid utilization by deaf-blind children is a lack of consistency between behaviors required at home and at school. This lack of a unified approach to audiologic rehabilitation adds to the child's apparent lack of response to amplification. However, younger children usually adapt to amplification easier than older ones, thus adding another argument in the case for early intervention with handicapped children.

In light of the serious problems associated with the use of amplification with the deaf-blind, the following recommendations and suggestions are made:

1. Teachers and parents should periodically discuss specific techniques for improved hearing

aid usage. Parental concerns about the child's apparent discomfort associated with amplification should be handled directly and honestly. Suggestions should be made regarding what type of acoustic environment with which to provide the child as well as how to adjust the gain level.

2. A plan for an auditory training program and a means of assessing progress in the child's utilization of amplification should be systematically developed by the audiologist in conjunction with parents, the teacher, and other professionals from various disciplines.
3. Parents should be counseled regarding the importance of hearing aid usage by the child. A commitment on the part of the parents and teachers to the philosophical reasons behind the recommendations made is important. This commitment can be better reinforced through participation of parents and teacher in the development of a management plan.
4. Coordination between school and home should be improved to ensure consistency of techniques and goals. Otherwise, parents may be unknowingly reinforcing behaviors which the school is trying to eliminate. Many times social workers and nurses are able to provide the bridge between school activities and home activities.

Implications and Interpretation of Audiometric Results

An important role of the audiologist in dealing with the deaf-blind is in counseling parents regarding the nature, extent, and implications of the child's hearing impairment. Demonstrations of simulated hearing loss are often helpful in fostering understanding of the types of distortions which a severe sensorineural hearing loss might produce. Parents who observe audiologic testing of their child often report a clearer understanding of the audiologist's report and a better appreciation of the recommendations. When a hearing aid is recommended, the audiologist may want to give the parents an opportunity to handle the hearing aid to gain confidence in their ability to fit the earmold in their child's ear, set the gain control, and check the efficiency of the battery.

In addition to counseling the child's parents regarding the results of the audiometric examination, audiologists need to make themselves available to interpret audiometric findings to professionals from other disciplines and to answer questions which might arise concerning the audiologic

recommendations. An audiologist working as part of a team soon learns to speak in commonsense terms about the abilities and limitations of the child's auditory system. Our experience has been that audiometric recommendations for deaf-blind children many times must be reconsidered and modified to complement the recommendations of physicians, social workers, teachers, psychologists, and other professionals. The audiological report should include statements regarding the appropriateness of an auditory training program with a particular child. Furthermore, in terms of setting realistic educational objectives, the audiologist should consult with the teacher regarding expectations of an auditory training program and how these expectations are (or are not) consistent with the audiologic findings.

A serious consideration in the educational programming of the deaf-blind is in the determination of the appropriateness of oral communication for a particular child. Few congenitally deaf-blind children are able to master oral communication. In spite of this, the child's ability to utilize sounds in a meaningful way must be assessed carefully. So critical is the need to establish a language system within the child that in all cases of a severe dual sensory impairment manual communication should be introduced either in conjunction with the auditory training program or as a separate educational unit.

The effects of an auditory disorder on a visually-impaired child intensify the magnitude of his or her medical, social, and educational problems to such a large extent that traditional disciplinary approaches to management planning are not meaningful or applicable. The multihandicapped child requires a multidisciplinary team, functioning in an interdisciplinary way. Only through such a team effort, rather than a series of disciplinary evaluations and recommendations, can a realistic program which considers the total child and his or her environment be implemented.

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The Ophthalmologist and Educator: Their Interactions in the Care of the Deaf-Blind Child

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A survey of the anatomy and physiology of the visual system is presented as an introduction to this section of the state-of-the-art report. For a more comprehensive treatment of this topic, the reader is referred to one of the basic textbooks in ophthalmology (Scheie and Albert, 1969). Effort will be made to stress the ocular pathophysiology of the more common diseases which simultaneously affect the visual and auditory systems.

Anatomy and Physiology of the Visual System

The functional part of the eye actually begins with the retina, a thin transparent membrane that lies on the inner surface of the eyeball. The retina is composed of photoreceptors and interconnecting neurons that transform a light stimulus into a nerve impulse and send it along cellular processes through the optic nerve to the brain. The primary function of each of the other parts of the eyeball is to receive and focus images of the outside world on the retina. Visual loss caused by disease can occur at the level of the retina, at any point along its visual pathway to the brain, or in any of the transparent structures in front of the retina. Parts of the eyeball are illustrated in Figure 1.

Cornea and Sclera

The wall of the eyeball is composed of strong collagenous fibers. In the transparent anterior portion of the globe, or cornea, the fibers are arranged in a regular pattern that allows light to enter without being disturbed. The sclera, or "white of the eye," is opaque because of reflected light from the irregular arrangement of the collagenous fibers that make up its layers.

The transparency of the cornea is maintained by an active process. A single layer of cells, the corneal endothelium, which lines the cornea's inner

surface, serves as a metabolic pump to maintain the cornea in a relatively dehydrated state. Any process that interrupts or disturbs the corneal endothelium interferes with its function. The result is corneal swelling (edema) and clouding caused by distortion of the regular arrangement of the collagenous fibers that are necessary for transparency. Elevated intraocular pressure (glaucoma) is occasionally a part of the congenital rubella syndrome. In this situation, as in many other cases of congenital glaucoma, corneal edema manifested as corneal clouding and decreased vision is a result. The eye and its related structures are illustrated in Figure 2.

Anterior Chamber

The anterior chamber is a fluid-filled space bounded anteriorly by the cornea and posteriorly by the iris and lens. This small chamber of the eye is filled with an ultrafiltrate of serum, the aqueous. The anterior chamber angle, which is formed at the point where the iris meets the cornea, contains the drainage system for the aqueous produced inside the eye. Congenital glaucoma is a result of the failure of the anterior chamber angle to develop normally. Without a functional drainage system, intraocular pressure builds to high levels and results in corneal edema and damage to the eye.

Iris

The iris is a structure that serves to control the amount of light entering the eye. It is composed of loose connective tissue containing numerous pigmented cells. The irises in blue eyes contain relatively small amounts of pigment; those in darker eyes contain relatively more pigment. Two iris muscles control the shape of the pupil. They are the sphincter, a circumferential bundle at the

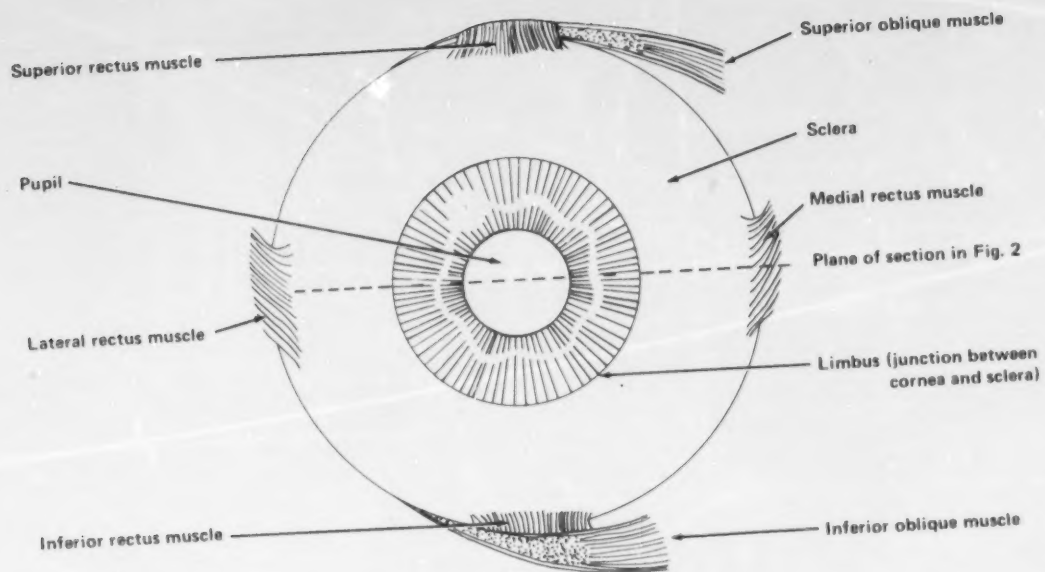


Fig. 1. Parts of the eyeball

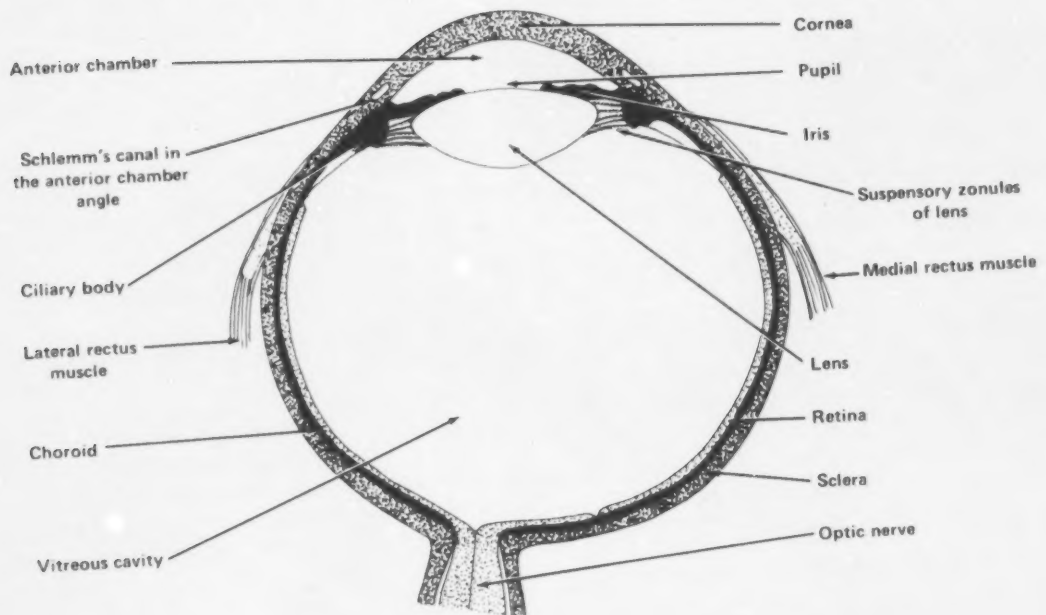


Fig. 2. The eye and its related structures

pupillary margin, and the dilator, a thin muscle that runs radially from the edge of the pupil to the root of the iris. Bright light stimulates a reflex contraction of the sphincter muscle of the iris, and the contraction causes the pupil to become narrow. Dim light allows the sphincter to relax while the dilator muscle acts to cause pupillary dilation.

Lens

The lens, which is a biconvex transparent mass the size of a small grape, lies immediately behind the iris. The lens is held in place by zonules, suspensory fibers arising from the ciliary body just posterior to the point where the iris and cornea meet. Contraction and relaxation of muscles in the ciliary body allow the lens to change shape and alter its ability to focus light rays. The ability of the lens to change shape is referred to as accommodation. As the lens becomes round, it brings near objects into clear focus on the retina. When the gaze is shifted to distant objects, the lens assumes the shape necessary for clear viewing.

A cataract is any opacity or clouding of the lens. The opacity can assume any shape and affect part or all of the lens. The lens develops during embryonic life by the deposition of successive layers of lens fibers. In maternal rubella infections, retardation of embryonic lens growth interferes with the normal lens transparency. After the infection has been resolved, subsequent layers of lens growth will be normal. As a result, the newborn infant with congenital rubella infection that occurred during the first three months of embryonic life will demonstrate an opacity in the center of the lens. In this way the time of the infection can be documented by the location and the extent of the opacity in the lens, much like the rings of a tree indicate certain deductions during the growth of the tree.

Choroid and Vitreous

A layer of pigmented vascular tissue continuous with the iris lines the inner surface of the globe. Posteriorly, this layer is referred to as the choroid. It contains the vascular and nerve supply for the overlying retina. The vitreous is a transparent gel that occupies the space inside the globe posterior to the lens.

Retina and Optic Nerve

The retina, the functional unit of the eye, lies on the inner surface of the eyeball. The photoreceptors or rods and cones of the retina receive light impulses and transform them into impulses that are

transmitted toward the brain. The two types of photoreceptors, rods and cones, are named for their shape and have different specialized functions. Rods are sensitive to low illumination and are primarily responsible for night vision. The differentiation of color as well as the ability to see in bright illumination are functions of the cones. The peripheral retina is populated primarily by rods and is responsible for side vision. Sharp central visual acuity is almost exclusively a function of the cones.

The differential functions of the photoreceptor cells are important clinically. Retinitis pigmentosa, the cause of visual loss in Usher's syndrome, is an isolated rod dystrophy. After a certain period of time of normal function, the rod portions of the photoreceptors die prematurely. This is manifest clinically by night blindness and progressive constriction of the peripheral visual field. The fact that central visual acuity, color vision, and day vision are affected relatively less is a consequence of the preservation of cone function in this disorder.

Destruction or damage to the optic nerve results in atrophy of the nerve fibers carrying the visual impulses. Although the photoreceptors in the retina may be normal, optic atrophy may lead to blindness. Optic atrophy may be a primary inherited disorder or secondary to compression of the optic nerve and its blood supply. One example of the latter situation occurs in craniofacial dysostosis in which there is maldevelopment of the bones of the skull.

The optic nerves terminate in the optic chiasm where some of the fibers in the nerve cross to the opposite side. Posterior to the chiasm the entire left visual field is carried along the right optic radiations. A final synapse in the lateral geniculate body sends the visual impulse to the occipital cortex where the visual image is recorded by the brain.

Generalized Disorders of the Eye

Poor vision may result from inability of the cornea and lens to focus light rays sharply on the retina. If, for example, the eye is longer than it should be, the light rays will be focused at some point in front of the retina. This condition, axial myopia or nearsightedness, may be a significant visual handicap for a young child. Only objects close to the eye will be imaged clearly. Although myopia can be corrected with spectacles, its frequent association with congenital hearing loss warrants a careful refraction in any child in whom

there is the combination of congenital hearing and visual impairment.

Developmental and Genetic Abnormalities

Developmental or genetic abnormalities are the most frequent causes of combined hearing and visual loss after congenital rubella infections. Specific entities are referenced in Table 1. Space does not allow details of all the genetic syndromes to be presented here. The reader is referred to the references in Table 1 for further information; however, some general observations on the pathophysiology of some of these lesions are included here.

The mucopolysaccharides are a group of disorders in which an abnormal accumulation of a mucopolysaccharide occurs in the cells of the body. Deposition of this substance, largely in the cells of the cornea, accounts for corneal haze and clouding, which cause poor vision. In sphingolipid-

osis, storage material is primarily localized in the ganglion cells of the retina. The destruction of these cells leads to an interruption in the visual pathway and to blindness. Congenital cataracts present in congenital rubella and other syndromes interfere with the passage of light into the eye. Instead of being focused normally, light is scattered by the opacity in the lens, and adequate vision is not possible.

Role of the Ophthalmologist as It Relates to the Deaf-Blind Child

The role of the ophthalmologist in the care of the deaf-blind child differs little in the broad sense from the care of any other patient with subnormal vision. However, specific responsibilities which the ophthalmologist should assume in this situation include special attempts at an accurate diagnosis, determination of visual acuity, and provision of early treatment and/or genetic counseling.

Table 1
Diseases Causing Combined Visual and Hearing Loss

		Visual impairments	
		Congenital	Onset in childhood
Hearing impairments	Congenital	Congenital rubella syndrome (Cooper and others, 1969) Hearing loss and high myopia (Roberts, 1970) Holmes-Schepens syndrome (Holmes and Schepens, 1972) Saddle nose, hearing loss, myopia (Marshall, 1958) Cochlear deafness and high myopia (Eldridge and others, 1968) Congenital cytomegalovirus infections	Usher's syndrome (Vernon, 1969; Cherry, 1973) Congenital deafness and progressive optic atrophy (Konigsmark and others, 1974)
	Onset in childhood	Norrie's disease (Warbarg, 1963) Flynn-Aird syndrome (Flynn and Aird, 1965)	Refsum's syndrome (Steinberg, 1970, 1972) Alstrom's syndrome (Alstrom, 1959) Laurence-Moon-Biedl syndrome (Burn, 1950) Cockayne's syndrome (Cockayne, 1936) Progressive hearing loss and optic atrophy (Rosenberg and Chutorian, 1967; Tunbridge and Paley, 1956) Mucopolysaccharidosis (Dorfman and Matalon, 1972) Sphingolipidosis (Goldberg, 1974) Craniofacial dysostosis (Bertelsen, 1958)

The details of the history and diagnostic examination will be discussed only where departures from normal procedure or special studies are indicated when examining a child with combined visual and hearing defect.

Family History

Family history is an important part of the diagnostic evaluation. Careful questioning should be directed to the mother to determine if she had a rubella infection during the first three months of pregnancy. Parents should be asked to describe when and how they noticed that the child had difficulty seeing. The time relationship between the onset of hearing and the first evidence of visual difficulty may be helpful in making a diagnosis. (See Table 1.) Specific questions should be directed to the parents to determine if the child was premature. High oxygen levels can be associated with retrolental fibroplasia. Recent studies have indicated that the noise in incubators may be close to the danger zone (Seleny and Streczyn, 1969).

The family history is extremely important in situations in which there is a combined visual and hearing defect. With the exception of the congenital rubella syndrome and the other less common congenital infections, all of the other causes of the combined hearing and visual problems (Table 1) are a result of genetic influences. The ophthalmologist should make considerable effort to obtain all of the available details of the family history. Especially important are the presence in the family of other affected members, the exact relationships between the patient and those persons, and the presence or absence of consanguinity. Documentation of a blood relationship between the parents of the affected child or the presence of common last names on both sides of the pedigree provides strong evidence for consanguinity. The type, onset, and cause of visual or hearing loss of any other family members should be thoroughly documented. Eye examinations should be performed on any family member suspected of having the disorder. Special attention should be paid to the possible presence of high myopia (nearsightedness), constricted visual fields, night blindness, obesity, hypogenitalism, degenerative neurological disorders, abnormal skull shapes, and history of a maternal male relative having an eye enucleated as a small child because these things would indicate the presence of Norrie's disease. The ophthalmologist should not hesitate to call in a geneticist as a

consultant if there are any unresolved questions about the family history.

Diagnostic Examination

The examination of the affected child may be difficult in the doctor's office because of the child's age, multiple handicaps, and lack of cooperation. Because of the necessity of establishing a diagnosis, examination under anesthesia should be scheduled unless the anesthesia would impose grave medical risks to the child. Certain portions of the examination, however, can be done only in the office. These include estimation of visual acuity and the examination of voluntary extraocular movements and pupillary responses.

Visual acuity determinations in young or handicapped children unfortunately are often limited to evaluation of the relative acuity in each eye. If only one eye has good visual acuity, the child will not object to having his poor eye covered but will object vigorously if his "good" eye is occluded (von Noorden and Maumenee, 1973). Once the child has reached age two-and-a-half to three years, and if he is sufficiently cooperative to perform the "E" game, determination of visual acuity can be done (von Noorden and Maumenee, 1973). The "E" game is often not possible, however, in the mentally retarded or multihandicapped child. The use of food symbols for determining visual acuity is described by Dunn and Smith (1965). A modification of this technique has been described as a technique for visual appraisal of mentally retarded children (Lawson and Schoofs, 1971). The patients in their series ranged from ages three to twenty-two years and all had an intelligence quotient of 60 or less. Even with their methods, 26 of 103 patients could not be tested.

Sheridan (1960, 1963, 1969) has developed a series of screening tests for young children and retardates (STYCAR). The acronym STYCAR is used to refer to these vision tests. Several different tests are described, such as the matching of distant letters or pictures to other letters or pictures placed on a table. The graduated balls tests (Sheridan, 1969) were developed to provide a reliable and repeatable assessment of the visual acuity of normal children from ages six months to two-and-a-half years, handicapped children unable to cooperate with matching tests, mentally retarded children, and children with language difficulties.

The use of the graduated balls test might prove especially valuable in testing the hearing-impaired

child who is suspected of having a visual abnormality. None of the other methods for subjectively measuring visual acuity have been consistently useful in testing this group of patients.

Once an assessment of visual acuity has been made, the ophthalmologist has a baseline upon which a diagnosis can be based when the findings of the examination under anesthesia and the refractive error are known. (Retinoscopy for determination of any refractive error is a routine part of the examination under anesthesia.) Any opacity in the ocular media (i.e., corneal opacity, cataract, or retrolental mass), which can safely be treated surgically should be treated as early as possible. Delay in treatment can result in permanent decreased vision secondary to deprivation amblyopia (von Noorden and Maumenee, 1968). If cataract surgery is performed on a young child, contact lens correction should be made as soon as possible. If correction is not made after such surgery, the child will develop irreversible visual loss from deprivation amblyopia just as if the cataract had not been removed.

After a diagnosis has been reached, the ophthalmologist must assume the role of counselor to the parents and teachers of the child. The ophthalmologist should convey to the family the nature of the problem; the cause, if known; the necessary treatment; and the prognosis. If the disorder is inherited, genetic counseling should be arranged for the family.

Communication Between Ophthalmologist and Educator

Ficociello (1974) concludes that a child's visual functioning can be assessed only in terms of the child's environment and the tasks he or she must perform in that environment.

Effective communication is essential for a strong working relationship between the educator and ophthalmologist. Each must make available to the other all information concerning the child as well as keep the other aware of any need for further data. This level of effective communication requires time, effort, and planning.

The ophthalmologist obtains objective information concerning the cause of the child's visual difficulties from the child's history and from the examination as described previously. The doctor needs help from the educator, however, in evaluating the visual functioning of the child. To expect the multihandicapped child to demonstrate his or her highest level of visual functioning on cue in the

doctor's office is unreasonable. Diagnosis and prognosis are more accurate when data on the visual functioning of the child are available to compare with the objective findings at the time of examination.

The educator, observing the child in his or her everyday environment, has the responsibility for recording the level of visual functioning achieved by the child and making data available to the ophthalmologist. On the other hand, the educator needs information about the diagnosis, the achievable level and type of vision, the need for visual aids (glasses, contact lenses, low vision aids, and so forth), and the expected final visual outcome in order to plan a beneficial educational program for the child.

In any request for consultation from one medical specialist to another, all of the information available to the referring doctor, together with specific requests for information from the consultant, accompanies the patient on the first visit to the consultant. The educator's role is that of a referring specialist whose responsibilities should be the same. All pertinent information available to the educator and any requests for information should accompany the child on the visit to the ophthalmologist.

Suggested forms for the "providing and requesting" process are presented beginning on page 78. Revisions should be made to fit the individual situation. Form 1 for the educator's assessment of visual functioning draws heavily on the techniques described by Ficociello (1974) in her *Manual for Visual Assessment Kit*. This publication would be extremely useful as a guide in assessing visual functioning. A representative but limited number of tests were selected for inclusion in the information form. The effectiveness of such a report to the ophthalmologist diminishes as its length increases. Effort should be directed toward relevancy and conciseness.

Form 2 on page 80 is the suggested request for information from the ophthalmologist. Only pertinent information should be requested. Effort to avoid unnecessarily long and complicated forms will result in greater cooperation.

Ophthalmologists deal in such a specialized field that many of the words and abbreviations used by them may be unfamiliar to the educator. A list of commonly used abbreviations and their meanings is presented on page 81. In addition, terms relating to the eye and to eye disease are listed on page 72.

Low-Vision Aids

Optical aids are devices that help to correct or improve visual acuity. The most common optical aid is the conventional spectacle. Other low-vision aids for distance vision include telescopic and pinhole spectacles, modified spectacles, contact lenses, and nonspectacle aids such as binocular field glasses. Aids for near vision include reading glasses, bifocals, hand-held and stand magnifiers, and telescopic devices. Most low-vision aids improve vision by magnifying the image on the retina.

Even if one could assume that the deaf-blind child could use and would accept these low-vision aids, the diseases in which they are helpful are limited. Fonda (1970) lists disorders in the deaf-blind child in which low-vision aids are helpful. High myopia and surgical aphakia are the two most common situations in which low-vision aids might be helpful. Unfortunately, the retinitis pigmentosa group of diseases (Usher's, Refsum's, Alstrom's, Cockayne's, and Laurence-Moon-Bardet-Biedl syndromes) and those associated with optic atrophy respond poorly to low-vision correction. Visual correction in children with retinitis pigmentosa is difficult and unlikely because of the constriction of their peripheral visual fields.

The acceptance of low-vision aids among the mentally retarded deaf-blind children may be severely limited. However, each child who potentially may have an improvable level of visual functioning should be exposed to the use of appropriate low-vision aids.

Usually, low-vision aids are dispensed by a specialist, more commonly an optometrist, but often by an ophthalmologist running a low-vision clinic in association with a large medical center or medical school. If the consulting ophthalmologist believes that low-vision aids may benefit the child, he or she will send the child to the appropriate specialist.

The available literature in the field of low-vision aids is extensive; however, very little is written in this area specifically for the child with a combined hearing and visual defect. An annotated bibliography on low vision was compiled by Weiner (1973) at the University of Alabama in Birmingham. The bibliography begins with the year 1960 and is divided into four categories: epidemiology, examination techniques, clinical treatment, and rehabilitation and special education.

Two of the excellent textbooks in the field are *The Low-Vision Patient* (Faye, 1970), and *Management of the Patient with Subnormal Vision*, (Fonda, 1970). Dr. Faye devotes one section of her

book to a description of the child with partial sight. Often elementary school-age children are able to see print on objects held a few inches from their eyes without the use of glasses even with vision as low as 20/200 because of their ample powers of accommodation. Some children with vision of less than 20/200 may require low-vision aids, such as hand magnifiers, low-vision lenses, large-print books, or small monocular telescopes.

As children approach high school age, the power of accommodation drops off to the point at which holding material close to the eye may become excessively fatiguing. Low-vision aids may then become necessary for the first time.

Problems with low-vision aids in children may be a result of blurring of surroundings and distance vision when a strong plus lens is used. With a very strong lens, the field of vision is reduced to a few words or pictures.

The only advantage of large-type print is that material can be held farther from the eye. This advantage is questionable when the same magnification can be achieved by holding regular print 3.2 inches closer to the eye than large print. Disadvantages of the large-type books include increased size, weight, number of volumes, and cost.

A description of optical aids currently available is discussed in greater detail by Fonda (1970). Space does not allow reproduction of these excellent chapters, and any synopsis would be an unacceptable simplification. Any educator who is dealing with a multihandicapped child for whom a visual aid (including strong glasses) has been prescribed is referred to this source for specific information.

A few basic facts about visual aids commonly used may be helpful. Spectacle aids have a set working distance which is closer to the eye than normal. Only at this close distance will material be in focus. Hand magnifiers must be held between the eye and the object to be effective. The largest image is obtained at the maximum distance that will allow a sharp focus on the material. Stand magnifiers that rest on the page require a relatively normal working distance. Children with certain strong reading lenses may not be able to use them. Telescopic devices may be used for distance vision, such as for viewing the blackboard, but the field is restricted and the child may subsequently lose his or her place easily.

Sources of optical aids, accessory equipment (e.g., lamps, reading stands, and so forth), education and reference material, as well as the addresses of suppliers are included in Appendix C of Dr. Faye's text.

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Vocabulary of Terms Relating to the Eye¹

- Accommodation**—The adjustment of the eye for seeing at different distances, accomplished by changing the shape of the crystalline lens through action of the ciliary muscle, thus focusing a clear image on the retina.
- Albinism**—An hereditary loss of pigment in the iris, skin, and hair; usually associated with lowered visual acuity, nystagmus and photophobia and often accompanied by refractive errors.
- Amblyopia**—Dimness of vision without any apparent disease of the eye.
- Amblyopia Ex Anopsia**—Dimness of vision due to disuse of the eye.
- Ametropia**—A refractive error in which the eye when in a state of rest does not focus the image of an object upon the retina; includes hyperopia, myopia, and astigmatism. See Refractive error.
- Aniridia**—Congenital absence of the iris.
- Aniseikonia**—A condition in which the ocular image of an object as seen by one eye differs in size or shape from that seen by the other eye.
- Anophthalmos**—Absence of a true eyeball.
- Anterior chamber**—Space in the front of the eye, bounded in front by the cornea and behind by the iris; filled with aqueous.
- Aphakia**—Absence of the lens of the eye.
- Aqueous**—Clear, watery fluid which fills the anterior and posterior chambers within the front part of the eye.
- Asthenopia**—Eye fatigue caused by tiring of the internal or external muscles.
- Astigmatism**—Refractive error which prevents the light rays from coming to a single focus on the retina because of different degrees of refraction in the various meridians of the eye.
- Binocular vision**—The ability to use the two eyes simultaneously to focus on the same object and to fuse the two images into a single image which gives a correct interpretation of its solidity and its position in space.
- Blepharitis**—Inflammation of the margin of the eyelids.
- Blindness**—In the United States, the legal definition of blindness is: central visual acuity of 20/200 or less in the better eye after correction; or visual acuity of more than 20/200 if there is a field defect in which the widest diameter of the visual field subtends an angle distance no greater than 20 degrees. Some states include up to 30 degrees.
- Buphthalmos**—Large eyeball in infants—generally due to secondary glaucoma.
- C, CC (Cum correction)**—With correction, wearing prescribed lenses.
- Canal of Schlemm**—A circular canal situated at the juncture of the sclera and cornea through which the aqueous is excreted after it has circulated between the lens and the iris and between the iris and the cornea.
- Canthus**—The angle at either end of the slit between the eyelids; specified as outer, or temporal, and inner, or nasal.
- Cataract**—A condition in which the crystalline lens of the eye, or its capsule, or both, become opaque, with consequent loss of visual acuity.
- Central visual acuity**—Ability of the eye to perceive the shape of objects in the direct line of vision.
- Chalazion**—Inflammatory enlargement of a meibomian gland in the eyelid.
- Chorioretinitis**—Inflammation of the choroid and retina.
- Choroid**—The vascular, intermediate coat which furnishes nourishment to the other parts of the eyeball.
- Choroiditis**—Inflammation of the choroid.
- Ciliary body**—Portion of the vascular coat between the iris and the choroid. It consists of ciliary processes and the ciliary muscle. (See Uvea.)
- Coloboma**—Congenital cleft due to the failure of the eye to complete growth in the part affected.
- Color deficiency**—Diminished ability to perceive differences in color—usually for red or green, rarely for blue or yellow.
- Concave lens**—Lens having the power to diverge parallel rays of light, also known as diverging, reducing, negative, myopic, or minus lens, denoted by the sign —.
- Cones and rods**—Two kinds of cells which form a layer of the retina and act as light-receiving media. Cones are concerned with visual acuity and color discrimination; rods, with motion and vision at low degrees of illumination (night vision).

¹*Vocabulary of Terms Relating to the Eyes*. New York: National Society for the Prevention of Blindness, Inc., 1972.

Congenital—Present at birth.

Conjunctiva—Mucous membrane which lines the eyelids and covers the front part of the eyeball.

Conjunctivitis—Inflammation of the conjunctiva.

Contact or corneal lenses—Lenses so constructed that they fit directly on the eyeball; used for the correction of vision in cases having a cone-shaped cornea and for cosmetic reasons. Corneal lenses are also used after cataract (lens) extraction to replace the lens removed from the eye. They provide less distortion and image size difference from the other eye than spectacles would.

Convergence—The process of directing the visual axes of the two eyes to a near point, with the result that the pupils of the two eyes are closer together. The eyes are turned inward.

Convex lens—Lens having power to converge parallel rays of light and to bring them to a focus; also known as converging, magnifying, hyperopic, or plus lens, denoted by sign +.

Cornea—Clear, transparent portion of the outer coat of eyeball forming front of aqueous chamber.

Corneal graft—Operation to restore vision by replacing a section of opaque cornea with transparent cornea.

Crystalline lens—A transparent, colorless body suspended in the front of the eyeball, between the aqueous and the vitreous the function of which is to bring the rays of light to a focus on the retina.

Cyclitis—Inflammation of the ciliary body.

Cycloplegic—A drug that temporarily puts the ciliary muscle at rest and dilates the pupil; often used to ascertain the error of refraction.

Cylindrical lens—A segment of a cylinder, the refractive power of which varies in different meridians; used in the correction of astigmatism.

Dacryocystitis—Inflammation of lacrimal sac.

Dark adaptation—The ability of the retina and pupil to adjust to a dim light.

Depth perception—The ability to perceive the solidity of objects and their relative position in space.

Diopter—Unit of measurement of strength or refractive power of lenses.

Diplopia—The seeing of one object as two.

Duction—A stem word used with a prefix to describe the turning or rotation of the eyeball (abduction—turning out, adduction—turning in).

Dyslexia—Inability to read which is apparently due to a neurological problem.

Ectropion—An eversion or turning inside out of the eyelid.

Emmetropia—The refractive condition of the normal eye. When the eye is at rest, the image of distant objects is brought to a focus on the retina.

Endophthalmitis—Inflammation of most of the internal tissues of the eyeball.

Entropion—A turning inward of the eyelid.

Enucleation—Complete surgical removal of the eyeball.

Esophoria—A tendency of the eye to turn inward.

Esotropia—A manifest turning inward of the eye (convergent strabismus or crossed eye).

Exophoria—A tendency of the eye to turn outward.

Exophthalmos—Abnormal protrusion of the eyeball.

Exotropia—Abnormal turning outward from the nose of one or both eyes (divergent strabismus).

Extrinsic muscles—External muscles of the eye which move the eyeball. Each eye has four rectus and two oblique muscles.

Eye dominance—Tendency of one eye to assume the major function of seeing, being assisted by the less dominant eye.

Eye grounds—See Fundus.

Field of vision—The entire area which can be seen without shifting the gaze.

Floaters—Small particles consisting of cells or fibrin which move in the vitreous.

Focus—Point to which rays are converged after passing through a lens; focal distance is the distance rays travel after refraction before focus is reached.

Fornix—A loose fold of the conjunctiva where the part covering the eyeball meets the conjunctiva lining of the eyelid.

Fovea—Small depression in the retina at the back of the eye; the part of the macula adapted for most acute vision.

Fundus—The back of the eye which can be seen with an ophthalmoscope.

Fusion—The power of coordinating the images received by the two eyes into a single mental image.

Glaucoma—Increased pressure inside the eye; "hardening of the eyeball," caused by accumulation of aqueous fluid in the front portion.

Glioma—Malignant tumor of the retina.

Gonioscope—A magnifying device used in combination with strong illumination and a contact glass for examining the angle of the anterior chamber.

Hemianopsia—Blindness of one-half of the field of vision of one or both eyes.

Heterophoria—A constant tendency of the eyes to deviate from the normal position for binocular fixation, counterbalanced by simultaneous fixation forced by muscular effort (prompted by the desire for single binocular vision). Deviation is not usually apparent, in which case it is said to be latent.

Heterotropia—An obvious or manifest deviation of the visual axis of an eye out of alignment with the other eye. Syn. *cross-eye*; *strabismus*.

Hydrophthalmus (congenital glaucoma)—A rare congenital defect in which the eyeball is abnormally large. Iris present at birth or develops early in infancy.

Hyperopia, Hypermetropia—A refractive error in which, because the eyeball is short or the refractive power of the lens weak, the point of focus for rays of light from distant objects (parallel light rays) is behind the retina; thus accommodation to increase the refractive power of the lens is necessary for distant as well as near vision.

Hyperphoria—A tendency of one eye to deviate upward.

Hypertropia—A deviation upward of one of the visual axes.

Injection—A term sometimes used to mean congestion of ciliary or conjunctival blood vessels, redness of the eye.

Interstitial keratitis—Affection of the middle layer of the cornea; disease, found chiefly in children and young adults, is usually caused by transmission of syphilis from mother to unborn child.

Iridocyclitis—Inflammation of the iris and ciliary body.

Iris—Colored, circular membrane, suspended behind the cornea and immediately in front of the lens. The iris regulates the amount of light entering the eye by changing the size of the pupil.

Iritis—Inflammation of the iris; the condition is marked by pain, inflammation, discomfort from light, contraction of pupil, discoloration of iris. It may be caused by injury, syphilis, rheumatism, gonorrhea, tuberculosis, and so forth.

Ishihara Color Plates—A test for defects in recognizing colors, based on the ability to trace patterns in a series of multicolored charts.

Jaeger Test—A test for near vision; lines of reading matter printed in a series of various sizes of type.

Keratitis—Inflammation of the cornea; frequently classified as to type of inflammation and layers of cornea affected as "interstitial" keratitis or "phlyctenular" keratitis.

Keratoconus—Cone-shaped deformity of the cornea.

Keratoplasty—See Corneal graft.

Lacrimal gland—A gland which secretes tears; it lies in the outer angle of the orbit.

Lacrimal sac—The dilated upper end of the lacrimal duct.

Lacrimation—Production of tears.

Lagophthalmos—A condition in which the lids cannot be completely closed.

Lens—A refractive medium having one or both surfaces curved.

Light adaptation—The power of the eye to adjust itself to variations in the amount of light.

Light perception—(L.P.), ability to distinguish light from dark.

Limbus—Boundary between cornea and sclera.

Low-vision aids—Optical devices of various types useful to persons with vision impairment.

Macrophthalmos—Abnormally large eyeball, resulting chiefly from infantile glaucoma.

Macula lutea—The small area of the retina that surrounds the fovea and with the fovea comprises the area of distinct vision. Syn. *yellow spot*.

Megalophthalmos—Abnormally large eyeball present at birth (congenital).

Microphthalmos—An abnormally small eyeball present at birth (congenital).

Microscopic glasses—Magnifying lenses arranged on the principle of a microscope, occasionally prescribed for persons with very poor vision.

Miotic—A drug that causes the pupil to contract.

Mydriatic—A drug that dilates the pupil.

Myopia—Nearsightedness. A refractive error in which, because the eyeball is too long in relation to its focusing power, the point of focus for rays of light from distant objects (parallel light rays) is in front of the retina. Thus, to obtain distinct vision, the object must be brought nearer to take advantage of divergent light rays (those from objects less than twenty feet away).

Near point of accommodation—The nearest point at which the eye can perceive an object distinctly. It varies according to the power of accommodation.

Near point of convergence—The nearest single point at which the two eyes can direct their visual lines, normally about three inches from the eyes in young people.

Near vision—The ability to perceive distinctly objects at normal reading distance, or about fourteen inches from the eyes.

Night blindness—A condition in which the sight is good by day but deficient at night and in faint light.

Nystagmus—An involuntary, rapid movement of the eyeball; it may be lateral, vertical, rotary, or mixed.

Oculist or ophthalmologist—A physician—an M.D.—who specializes in diagnosis and treatment of defects and diseases of the eye, performing surgery when necessary or prescribing other types of treatment, including glasses.

Oculus dexter (O.D.)—Right eye.

Oculus sinister (O.S.)—Left eye.

Oculus uterque (O.U.)—Both eyes.

Ophthalmia—Inflammation of the eye or of the conjunctiva.

Ophthalmia neonatorum—An acute, purulent conjunctivitis in the newborn; (for control purposes, it is sometimes legally defined as "an inflamed or discharging eye in a newborn baby under two weeks").

Ophthalmologist or oculist—See Oculist.

Ophthalmoscope—An instrument used in examining the interior of the eye.

Optic atrophy—Degeneration of the nerve tissue which carries messages from the retina to the brain.

Optic chiasm—The crossing of the fibers of the optic nerves on the lower surface of the brain.

Optic disk—Head of the optic nerve in the eyeball.

Optician—One who grinds lenses, fits them into frames, and adjusts the frames to the wearer.

Optic nerve—The special nerve of the sense of sight which carries messages from the retina to the brain.

Optic neuritis—Inflammation of the optic nerve.

Optometrist—A licensed, nonmedical practitioner, measures refractive errors—that is, irregularities in the size or shape of the eyeball or surface of the cornea—and eye muscle disturbances. In his or her treatment the optometrist uses glasses, prisms, and exercises only.

Orthoptic training—Series of scientifically planned exercises for developing or restoring the normal teamwork of the eyes.

Orthoptist—One who provides orthoptic training.

Palpebral—Pertaining to the eyelid.

Pannus—Invasion of the cornea by infiltration of lymph and formation of new blood vessels.

Partially seeing child—For educational purposes, a partially seeing child is one who has a visual acuity of 20/70 or less in the better eye after the best possible correction, and who can use vision as his or her chief channel of learning.

Perimeter—An instrument for measuring the field of vision.

Peripheral vision—Ability to perceive the presence, motion, or color of objects outside of the direct line of vision.

Phlyctenular keratitis—A variety of keratitis characterized by the formation of pustules or papules on the cornea; usually occurs in young children and may be caused by poor nutrition. Many physicians believe it to be a tubercular condition.

Phoria—A root word denoting a latent deviation in which the eyes have a constant tendency to turn from the normal position for binocular vision; used with a prefix to indicate the direction of such deviation (hyperphoria, esophoria, exophoria).

Photophobia—Abnormal sensitivity to and discomfort from light.

Pleoptics—A method of treating amblyopia through the use of instruments which restore fixation to the fovea by direct stimulation or by the production and correct localization of after-images.

Posterior chamber—Space between the back of the iris and the front of the lens; filled with aqueous.

Presbyopia—A gradual lessening of the power of accommodation due to a physiological change which becomes noticeable after the age of forty.

Prosthesis—An artificial substitute for a missing eye (or other missing part of the body).

Pseudoisochromatic charts—Charts with colored dots of various hues and shades indicating numbers, letters or patterns, used for testing color discrimination.

Pterygium—A triangular fold of growing membrane which may extend toward the cornea on the white of the eye. It occurs most frequently in persons exposed to dust or wind.

Ptosis—A paralytic drooping of the upper eyelid.

Refraction—(1) deviation in the course of rays of light in passing from one transparent medium into another of different density; and (2) determination of refractive errors of the eye and correction by glasses.

Refractive error—A defect in the eye that prevents light rays from being brought to a single focus exactly on the retina.

Refractive media—The transparent parts of the eye having refractive power; cornea, aqueous, lens, and vitreous.

Retina—Innermost coat of the eye, formed of sensitive nerve fibers and connected with the optic nerve.

Retinal detachment—A separation of the retina from the choroid.

Retinitis—Inflammation of the retina.

Retinitis pigmentosa—An hereditary degeneration and atrophy of the retina. There is usually misplaced pigment.

Retinoblastoma—The most common malignant intraocular tumor of childhood occurs usually under age five. It is probably always congenital. (Formerly known as glioma).

Retinopathy—A disease of the retina, due to various causes.

Retinoscope—An instrument for determining the refractive state of the eye by observing the

movements of lights and shadows across the pupil by the light thrown onto the retina from a moving mirror.

Retrolental fibroplasia—A disease of the retina in which a mass of scar tissue forms on back of the lens of the eye. Both eyes are affected in most cases and it occurs chiefly in infants born prematurely who receive excessive oxygen.

Rods and cones—See Cones and rods.

S. SC (Sine correction)—Without correction; that is, not wearing glasses.

Safety glasses—Impact resistant; available with or without visual correction for workshop or street wear protection, for both adults and children.

Sclera—The white part of the eye—a tough covering which, with the cornea, forms the external, protective coat of the eye.

Scleritis—Inflammation of the sclera.

Scotoma—A blind or partially blind area in the visual field.

Slit lamp—Provides a narrow beam of strong light; often used with a corneal microscope for examination of the front portions of the eye.

Snellen Chart—Used for testing central visual acuity. It consists of lines of letters, numbers or symbols in graded sizes drawn to Snellen measurements. Each size is labeled with the distance at which it can be read by the normal eye. Most often used for testing vision at distance of 20 feet.

Spherical lens—Segment of a sphere refracting rays of light equally in all meridians.

Stereoscopic vision—Ability to perceive relative position of objects in space without such cues as shadow, size, and overlapping.

Strabismus—Squint; failure of the two eyes simultaneously to direct their gaze at the same object because of muscle imbalance.

Strophosymbolia—A disorder of perception in which objects seem reversed as in a mirror. A reading difficulty inconsistent with a child's general intelligence beginning with confusion between similar but oppositely oriented letters, (b-d, q-p) and a tendency to reverse direction in reading.

Stye—Acute inflammation of a sebaceous gland in the margin of the eyelid, due to infection and usually resulting in the formation of pus.

Sympathetic ophthalmitis—Inflammation of one eye due to an infection in the other eye.

Synechia—Adhesion, usually of the iris to cornea or lens.

Tangent screen—A large black or gray curtain supported by a framework on which the normal central field and blind spot have been lightly outlined. This instrument is used for measuring the central field of vision.

Tarsus—The framework of connective tissue which gives shape to the eyelid.

Telescopic glasses—Magnifying spectacles founded on the principles of a telescope; occasionally prescribed for improving very poor vision which cannot be helped by ordinary glasses.

Tension, Intraocular—The pressure or tension of the contents of the eyeball.

Tonometer—An instrument for measuring pressure inside the eye.

Trachoma—A form of infectious kerato-conjunctivitis caused by a specific virus which in the

chronic form produces severe scarring of the eyelids and cornea.

Tropia—A root word denoting an obvious deviation from normal of the axis of the eyes (strabismus) used with a prefix to denote the type of strabismus, as heterotropia, esotropia, exotropia.

Tunnel vision (Gun-Barrel, Tubular)—Contraction of the visual field to such an extent that only a small area of central visual acuity remains, thus giving the affected individual the impression of looking through a tunnel.

Uveal tract—Entire vascular coat of the eyeball. It consists of the iris, ciliary body, and choroid.

Uveitis—Inflammation of the uveal tract of the eye.

Vision—The art or faculty of seeing; sight.

Visual acuity—See Central visual acuity.

Visual purple—The pigment in the outer layers of the retina.

Vitreous—Transparent, colorless mass of soft, gelatinous material filling the eyeball behind the lens.

Vitreous opacities—See Floaters.

Form 1
Information Helpful to the Ophthalmologist in Evaluation
of the Hearing and Visually Handicapped Child

Personal Data

Name: _____

Date of birth: _____

Diagnosis known to educator: _____

Objective Information

Present classroom or learning situation: _____

Difficulties experienced by the child in that situation: _____

Is one eye turned in or out at all times? Yes No

Is one eye turned in or out intermittently or when the child is tired? Yes No

Have you noticed anything unusual about how his or her eyes look? Yes No

If so, please describe.

Assessment of Visual Function

1. Child blinks or moves when object is brought quickly toward his or her eyes Yes No

2. Child responds to flashlight turned on:

In front of face Yes No

To right Yes No

To left Yes No

Up Yes No

Down Yes No

Is the response in each case consistent? Yes No

3. Child reaches for 3-inch (or state size) balls or toys _____ inches
from his or her face.

4. Is the response to objects (Item 3 above) the same for all fields? Check upper right, upper left, lower right, and lower left. (Right refers to the child's right.) Present the objects from behind the child to avoid clues from your body or arm. Yes No

5. Does the child track (follow with head and/or eyes):

A balloon moved in his or her visual field? Yes No

Children's bubbles? Yes No

Life Savers on a string? Yes No

6. Does the child look at or reach for objects in front of him or her? Yes No

7. Can the child locate and pick up objects off the floor?

Small top? (3 inches or less) Yes No

M&Ms? Yes No

Raisins? Yes No

8. If three cardboard circles are presented, can the child match the two of the same color? Yes No

Smallest size circles the child can match:

9. Comment on any other similar visual functions which you have observed consistently and repeatedly in this child.

10. Has the child's behavior changed recently? Yes No

If yes, please describe. _____

11. Does the child have difficulty with fine and/or gross motor functions? Yes No

12. Additional comments which you feel may be relevant to this child's visual problem.

Form 2
**Summary of Ophthalmologist's Examination and Treatment
for Incorporation in Educational Plan**

Dear Doctor:

Your assessment of this child's disease, treatment, and prognosis will be valuable in future educational placement and training. Answers to the brief questions below would be most helpful in formulating the best possible educational program for this child.

I. Examination Results

- A. Diagnosis:
- B. Distance visual acuity:
- C. Near visual acuity:
- D. Is binocular vision and stereopsis present?

II. Treatment

- A. Medications prescribed and frequency:
- B. Are glasses helpful?
Contact lenses?
- C. Should glasses be worn constantly?
Only when reading?
- D. Suggested classroom changes
 - 1. Seating location:
 - 2. Lighting:
 - 3. Large-print books:
- E. Low-vision aid helpful?
- F. If prescribed, how should low-vision aid be used?

III. Prognosis

- A. Stationary or progressive visual loss?
- B. Anticipated end visual result if disease is progressive?
At what age?
- C. Is surgery a possibility now or in the future?

M.D.

Abbreviations Commonly Used by Ophthalmologists

- A or Acc*—Accommodation
AC or A/C—Anterior chamber
b.i.d.—Twice daily (used in reference to medication dosage)
BI or BO—Base in or base out (of a prism)
CF—Counts fingers: usually recorded with distance; counted as a measure of visual acuity
D—Diopter (lens strength)
E—Esophoria at distant point
E'—Esophoria at near point, 14 inches
EOM—Extraocular muscles
ET—Esotropia, or manifest deviation of the eyes at distance
ET'—Esotropia at near point
EUA—Examination or evaluation of an eye under anesthesia, commonly done with small or uncooperative children
H—Hyperphoria
HMO—Hand motions only
HT—Hypertropia
J₁—Reads Jaeger print No. 1
LPO—Light perception only, patient sees only light
NLP—No light perception, absolute blindness
NPC—Near point or convergence
OD or RE—Oculus dexter, right eye
OS or LE—Oculus sinister, left eye
OU—Oculi unitas, both eyes
PD—Pupillary distance—separation of the pupils in millimeters
PSC—Posterior subcapsular cataract (referring to localization of lens opacity)
q.d.—Daily (used in reference to medication dosage)
q.h.—Every hour (used in reference to medication dosage)
q.i.d.—Four times daily (used in reference to medication dosage)
q.o.d.—Every other day (used in reference to medication dosage)
RLF—Retrolental fibroplasia
SLE—Slit lamp examination
TA—Tension by applanation (referring to measurement of intraocular pressure by the applanation tonometer mounted on the slit lamp, for detection of glaucoma)
t.i.d.—Three times daily (used in reference to medication dosage)
ts—Intraocular pressure determined by the Schiotz tonometer instead of by applanation for detection of glaucoma
V, V_A—Visual acuity at distant point (20 feet)
V_N or V_A_{Near}—Near visual acuity (14 inches)
sc—Without correction, referring to vision obtained without glasses
cc—With correction, referring to vision obtained with glasses
V_A—Visual acuity, right eye (conventionally written on top); visual acuity, left eye (conventionally written below)
X—Exophoria at distant point (when fixation is at 20 feet)
X'—Exophoria at near point (when fixation is at 14 inches)
XT—Exotropia at distant point
XT'—Exotropia at near point

Clinical Evaluation of Deaf-Blind Children

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Persons working with the deaf-blind should keep in mind that they are not dealing with just a visually-and-hearing-impaired patient, client, or student but with a whole person. Patients have traditionally been looked at individually, and this has allowed for relatively easy acceptance and implementation of individualized, prescriptive programming within the medical setting.

Clinical evaluation can provide a method of looking at the total child both initially and in an ongoing program. This includes evaluation of the child's total health status, his or her developmental-educational levels, and his or her family and social environment. Because all of these factors may significantly affect the child's response to an educational program, evaluation and intervention should be accomplished as necessary. Any one of these factors may be significant enough to warrant modification of the child's educational program. Such modification might be required on a continuing basis, as with a severe cardiac involvement, or intermittently, as in the case of cataract surgery or a family crisis.

The deaf-blind child is a family member and as such shares its inherent strengths and weaknesses. He or she is also a member of a community which may or may not have resources available to meet his or her specific needs. Both of these factors may directly affect educational planning for the child. The effect of the family will be strong primarily in his or her early years; the effect of the community will be felt later. This means that specific educational planning must take into account both family and community resources.

Establishing a program, keeping it updated, and anticipating future needs necessitate the exploration, use, and growth of community resources to meet the child's emerging educational and social

needs. Maintaining the program requires a multidisciplinary team to gather information within each respective field.

To be of maximum use, this information must be brought together. This can be accomplished by communication between the various team members who evaluate and work with the child. The child is better served if all those concerned are aware of the child's problems and have some understanding of the significance of those problems.

The Child Study Center

The Child Study Center is a unit of the Department of Pediatrics, Oklahoma Children's Memorial Hospital, University of Oklahoma Health Services Center. This medical center serves as a referral unit for children with neurological, developmental, and school problems. A multidisciplinary team is used to evaluate each child.

The professional staff at the Child Study Center consists of a child neurologist (the director), pediatrician, psychologist, social worker, speech-language pathologist, teachers in the preschool deaf-blind and learning disabilities programs, a part-time physical therapist, and a teacher's aide with sign language skills. In addition, an ophthalmologist, audiologist, music teacher, and creative movement consultant visit regularly. A psychiatrist is available for on-site consultation when needed. Any other clinical consultation which seems needed (e.g., genetic, cardiology, endocrinology, dental, and dietetic) is available within the medical center.

Although the initial and ongoing evaluation models presented here are those used at the Child Study Center, they would be replicable in any setting as long as the individual child and his or her specific problems are the focus of all program

planning. The entire approach is child-problem oriented. The specific disciplines within the team may vary from program to program depending on the staff available. Optimally, medical, developmental-educational, and social-family aspects would be represented.

The Initial Evaluation

The following paragraphs will serve to describe the events that take place during initial and ongoing evaluation. The initial evaluation can be organized into fairly distinct steps: (a) family-social; (b) medical; (c) educational-developmental; (d) staffing; (e) interpretation; and (f) follow-up.

Family-Social Evaluation

The family-social evaluation represents one of the first contacts between the family and the Child Study Center. Both parents are requested to attend. The function of this is bilateral; the family learns something of us while we learn about them. The first few minutes are spent in conversation designed to put the family at ease and to allow them to ask questions about the center and what to expect.

Although the occupation of the parents, the family income, and family composition are important, the family-social evaluation is designed to elicit much more than routine information. Backgrounds of the parents are explored in an effort to understand them better as people as well as parents. Relationships of the family members to each other are explored. Male-female roles, parental roles, and sibling roles are discussed. An attempt is made to determine how the parents see the effect of the handicapped child on siblings and the feelings of siblings toward the handicapped child. The parents' feelings toward the handicapped child and toward each other may be expressed in this initial interview, although these usually surface later as the family becomes more familiar with the staff, especially the social worker.

At the close of this first session, which usually lasts from one and one-half to two hours, a summary is discussed with the parents. The family often helps to formulate this summary, which will be presented to the staff along with the social worker's evaluation. For the sake of confidentiality, specific details may not be discussed with the whole staff. The social worker, however, may interpret the findings and present an opinion as to their effect on the family and the child. Although much information can be obtained during this

initial evaluation, the findings can only serve as a guide for beginning program planning.

At the end of the first session, the parents are also asked to state their expectations of the evaluation being done for their child and what they hope will result. Recommendations are not made at this time.

Medical Evaluation

Each child receives a general physical examination. Since the Child Study Center is a referral center, much of the medical evaluation may have been done already, especially laboratory work. Unless a need is indicated, evaluation work already done will not be repeated but will be obtained from the primary physician and used in the total evaluation. In addition, ophthalmological, audiological, and otologic evaluations are completed routinely on the visually-and-hearing-impaired child. If further medical evaluations (e.g., suspected cardiac or dental or genetic problems) are indicated, these are obtained as needed.

In the early years of evaluation of deaf-blind children, skull X-rays and electroencephalograms (EEGs) were obtained routinely. However, our experience has been that the usefulness of these in terms of the yield of information was not enough to warrant routine use. They are now ordered only when clinically indicated. Skull films, for example, are ordered along with other tests if toxoplasmosis is suspected as an etiology because the presence of calcifications may be useful in helping establish the diagnosis (Miller, Seaman, and Remington, 1967). EEGs are obtained if a seizure disorder is suspected.

Because the primary function of the Child Study Center is to deal with developmental, educational, and neurological problems, a complete neurological-developmental evaluation is done in every case. The neurological examination includes (1) an assessment of the child's general orientation, alertness, activity level, and spontaneity; (2) speech; (3) handedness, and, if appropriate, whether the child knows right and left sides, directionality, and so forth; (4) cranial nerve function; (5) motor and reflex function; (6) cerebellar function; (7) extrapyramidal function; (8) autonomic function; and (9) growth and developmental milestones.

Evaluation to determine possible need for medication is also done. Some of these children have already been given various medications (usually without success) by their primary physician prior to referral here. The most frequent medication found by this clinic to be indicated is an anticonvulsant. Indication for medication for hyperactiv-

ity is infrequent. This may be due in part to the very young age of the child. If hyperactivity is present, the neurologist and the psychologist may attempt to decide whether this behavior represents a medical or a behavioral problem. Counseling with the parents and working directly with the child are tried first. If medication then seems indicated, it will be tried in addition to the above program.

Educational Evaluation

Educational evaluation is an extensive and integral part of our initial evaluation and becomes the key in outlining a program for the child. This part of the evaluation is usually done by one of the teachers, although in another setting it might be equally well done by another team member. Assistance is obtained regularly from the psychologist, speech pathologist, and physical therapist. Any other staff member may be called upon as needed.

Since the children who are referred as candidates for the deaf-blind program are usually three years of age or younger, developmental levels are usually assessed by observation rather than by specific psychological tests or the use of standardized scales. Formal tests may be administered, however, at the discretion of the chief psychologist.

In addition to the noting, charting, and recording of specific observations, a videotape is made during the educational evaluation. This videotape serves several purposes. It can be used during the staffing session to demonstrate various points about the child. It becomes a baseline for documentation and a comparison for progress. The videotape may be restudied as an aid in program planning and on occasion may be useful in picking up something missed during the initial observation and evaluation. For example, some aspect of motor development such as a particular way of using the hands may not have been noted initially but may be observed when reviewing the tape.

Staffing

The staffing session follows the initial evaluation of the child and the family. At this session team members analyze and then synthesize the information, observations, measurements, and thoughts which have been gathered during the evaluation process. Basically, this staffing session provides the closure for the first phase of the evaluation process and serves as an instrument for program planning.

The staffing session is attended by members of the staff and appropriate consultants. At the Child Study Center, a physician is usually the team

leader. In another setting, any team member might serve as leader. The social worker, child psychologist, program teacher, and speech and language pathologist attend routinely. If appropriate, other members of the team, such as the physical therapist or learning disability teacher, may be asked to attend. Individuals in the community who are or have been involved with the child, such as teachers at the nursery school that the child attends or is expected to attend, may, with the parents' knowledge, participate in the staffing session.

The components of this session are as follows:

- (1) A review of all the information obtained to date presented by the person who did the evaluation or an appropriate substitute.
- (2) Discussions and recommendations. Although directed, this is a relatively informal and free-flowing session. Anyone present may give input. Lively discussion and questioning is encouraged. However, an attempt is made to reach a group decision, particularly in regard to recommendations. However, the various team members must remain primarily responsible for specific decisions within their own fields.
- (3) Feasibility.

If recommendation is made that the child would be appropriately served in the Child Study Center program, several factors are considered. These include the specific needs of the child regarding actual time in the program, staff availability, whether such service seems realistic in view of what is known about the family, transportation, and whether or not some other agency might be of service in a total program for this particular child.

Some of the children in the program attend regular preschools. Some preschool programs are unwilling to take the handicapped child into their programs, but our experience has been that those who do accept handicapped children are very cooperative in understanding and programming for the child's total needs. In such a case a cooperative program with an exchange of information is arranged so the child can have optimum benefit from both. A cooperative program is often recommended to provide the child with this type of peer group contact.

Interpretation

During the staffing session, the decision is made regarding which staff member will do the interpretation. Initially, this was done by the physician alone, but after a period of time we recognized

that a better interpretation could be given if more staff members participated. Now it is usually done by the physician, the social worker, and the teacher who participated in the initial evaluation. Both parents are asked to attend. All findings, the staff's interpretation of the significance of findings, and recommendations are discussed. The parents are encouraged to ask questions. They are not asked to make an immediate decision about a recommendation if they are at all hesitant. Instead, the parents are asked to take home a copy of the recommendations that have been made and to consider them.

A positive approach must be taken at the interpretation session, and staff members must be honest and fair with the family in regard to their situation. Special effort is made to expose the family to the child's strengths as well as to the problems. We have seldom seen a child and family for whom nothing could be done. The positive approach, emphasizing strengths, suggests beginning a program at the child's present level of functioning and building on this with consecutive and sequential steps.

Parents often ask for specific labeling, particularly with regard to retardation, and for prognosis. Attempt is made to avoid this. Instead, the program is discussed in terms of short-range plans and possibly some long-term goals. My experience over the past ten years has been that early, unequivocal types of prediction almost invariably underestimate the child's potential. Further, too early a prognosis, especially if it seems poor, may actually handicap the child by reducing the likelihood of adequate programming and by introducing a negative expectancy factor.

The "let's start a program and wait and see" attitude, however, requires not only time for programming for the child but also time to be spent with the parents. From time to time many parents need to sit down with the physician or team leader and review the whole situation, including why predicting a ceiling for the child's development may be doing the child a disservice.

Follow-up

Follow-up involves three elements: (1) forwarding of information to the referring source and to other persons or agencies as the parents direct; (2) if a program other than one at Child Study Center has been recommended, a follow-up in approximately two weeks to see whether contact for services has been made; and (3) further contact

with the Child Study Center staff if parents accept the recommendation for a program here.

If the child enters the Child Study Center program, an agreement is drawn up between parents and staff. In the beginning of our preschool program, no formal agreement was made with the family; the child was simply brought into the school. As experience was gained with the families and children, we became convinced that parent involvement was absolutely necessary for maximum progress of the child. After two or three years of experience, we decided that parents would be required to sign an agreement stating what they would do as participants in the child's program. This served the purpose of getting the parents involved, but we soon recognized that this represented only half of the situation. As a result, an agreement is now designed by both parents and the staff member, usually a teacher, who will be primarily responsible for the child's program. This agreement is individualized for both child and family and includes certain bilateral commitments. (See the sample team agreement on page 91.) This cooperative agreement has worked out much better with regard to both actual parent involvement and their attitude toward it as they recognize that this is now a mutual commitment.

Agreements are subject to review and revision. Thus, the agreements serve as one guideline for ongoing program planning and encourage communication between parents and staff.

A cost analysis of the clinical evaluation at the Child Study Center was recently completed. In terms of the actual time spent, cost varies between \$400 and \$500. Usually this cost is paid with a combination of state and federal funds. No one is denied service on the basis of financial status. However, under certain financial circumstances, the family may be requested to pay a portion of the cost.

Ongoing Evaluation and Program Planning

The multidisciplinary team has two roles: first as a diagnostic-evaluation team and second as classroom resource personnel. The core group for ongoing program planning consists of the child, the teacher, the parent(s), and the social worker. Other team members are used as needed and act as facilitators to the program. Such an arrangement requires that each member be flexible enough to step out of traditional roles. The physician, for example, may need to come out from behind the

desk or examining table to meet the child and teacher in the classroom, and the floor may become the examining table. Or, teachers may go into the home.

The Child Study Center is fortunate in having the diagnostic-evaluation unit, including a medical unit, housed in the same facility as the deaf-blind preschool program. This facilitates the use of all staff members, and outside consultants such as an audiologist, ophthalmologist, music teacher, and movement specialist come regularly. While it may be easier with a staff housed together, the basic aspects of the model could be replicated even when all facilities are separated. The problem-oriented approach does not depend on all the staff being housed together. It can work in day schools, homes, or other agency programs. What it does require is communication among the various team members and, in particular, communication with the person primarily responsible for planning the child's program.

The initial evaluation is only the beginning. It cannot continue indefinitely to serve as a guide for the program. Updating of information for program planning needs to be continuous. On a day-to-day basis, this is done by the teacher. However, help that seems needed may be obtained at any time and from any area. Other members of the team must be available as the need arises. Consultants outside the immediate program should also be used to provide classroom and program input. The audiologist, ophthalmologist, and physical therapist are the most frequently used resource personnel, though psychologists and psychiatrists are also called upon frequently. Some of our teachers have a background of speech and language training. Otherwise, a speech and language pathologist-consultant would undoubtedly be called upon with great frequency. (The evaluation schedule on page 92 shows the use of team members in ongoing evaluation and program planning.)

From time to time the child will need to be reevaluated. The reevaluation is similar to the initial evaluation but is usually not as extensive. Reevaluation is generally called for in a situation in which milestones have been met and major changes may be needed in the child's program. For example, it might be done when the child is ready to be considered for a public school program. At this time, in addition to the developmental assessments that have been obtained, standardized psychological testing may be needed. Perhaps specific speech-language reevaluation will be done,

and audiologic assessment, if indicated, will also be done at this time. Then a staffing session, as previously described, will be held. (See the sample case history on page 93.)

A review of services offered and their suitability to the child and family may also prove helpful, since the program must be flexible enough to adjust to the changing needs of both the child and family as these needs arise. The social worker may be of special help since she or he maintains close contact with other team members and with the family. The social worker must recognize that families go through stages in dealing with their handicapped child, and she or he must be prepared to deal with these changes as they develop (Solomons and Menolascino, 1970). The overall aim of the family program is to assist the family to become more self-sufficient in meeting its own needs and those of the child.

Occasionally, the social worker may need to intervene in crisis situations in the family. Consultation, if needed, is used. In our experience, psychologists, psychiatrists, and psychiatric social workers have been called in, depending upon the specific situation. When a family crisis is great, the child's program may have to be deemphasized while the family crisis is resolved. A program must be flexible enough to permit this. Although the actual mechanics of a program contribute to its running smoothly, mechanics alone are not the key. Problem orientation helps keep the focus directed on the child and thus contributes to both the effectiveness and flexibility of the program.

Teachers, parent(s), and social workers function as partners in the core group, and levels of responsibility may shift. Parents may appropriately assume the lead role at times. This is a valuable dynamic in the development of the program for child and family. To do this well and to minimize interpersonal and interprofessional problems, one must again keep the child-problem-oriented goal in mind. Closeness of staff and regular communication such as weekly staff meetings help to identify possible problems so they can be addressed early.

New Programs

Our program to date has been fortunate in having enough administrative flexibility to initiate new aspects into the program as the need arises or as a particular staff member develops new skills.

During 1974-75 a sibling program was initiated. Siblings may influence a child's progress in the program, but this is the first time that space and staff have been available to start such a program.

This program was initiated by one of our teachers who has a special interest in the siblings of handicapped children. It seems likely that the need for a psychologist or someone specifically trained to deal with siblings will evolve as a result of this program.

Another new program facet that has been very successful is the use of a teacher's aide who is deaf. This aide works directly with the children, who seem to recognize a kinship. In addition, signing classes for parents are given in the evening both at the school and at home. Staff members, including secretaries, who do not sign are also taking lessons.

This year, for the first time since the Child Study Center program began, evening preschool is being conducted in response to the fathers' requests that a time be arranged so they could participate more fully in their child's program. This is a classroom situation and is separate from the monthly parent meetings.

Also, a weekly evening session is conducted for parents to improve speech and language skills. This session is designed to help them carry over this important function more successfully at home.

Parents involved in the program have devised a survey form for parents' use in evaluating our services. (The survey instrument is included on page 107.) This will enable us to address any obvious problem areas. A questionnaire had been used previously with a large group of parents, mainly parents of learning disabled children. Information gained from that questionnaire resulted in some changes in our approach to that group of children.

Alternative Models

To determine the types, availability, and use of clinical services for deaf-blind children in the United States, we made an attempt to survey existing clinical services. We contacted all Regional Centers for Services to Deaf-Blind Children as well as individuals involved in services to the deaf-blind, though not necessarily through regional programs. To the 230 forms sent out, only 74 responses were received. The results have been summarized and interpreted, but because of the small number of responses, no attempt was made to do a statistical analysis.

In the programs for which a response was received, a wide range of clinical services appears to be generally available. Table 1 shows the services available as reported by the agencies responding to the questionnaire. These services tend to fall within

two categories: (1) primary services available for specific day-to-day program planning; and (2) support services used for initial input rather than continuous planning on a daily basis. How any of these various services is used, that is, whether in a primary or in a support category, depends upon the individual program and the overall goal of that program. Table 2 shows availability and use of clinical service in primary and support categories.

One of the prime values and purposes of clinical information is its usefulness in determining services needed by the child not only as a patient, client, or student but also as a person. Categories are necessarily artificial divisions of service and must continuously interact to enhance the development of the total person. While quality of clinical service is difficult to determine, the ways in which services are used may reflect the quality of service provided. The use of clinical information is shown in Table 3.

Occasionally, the person responding to the survey added helpful notes. Most often these notes reflected the lack of communication between team members and/or lack of recognition of the value of the information in program planning. The following quotation from one of the surveys is representative of this problem: "Some people have been very cooperative in discussing the educational implications of the evaluation with me. Others react like I'm sticking my nose in where it doesn't belong." This attitude indicates that certain interdisciplinary barriers may need to be removed before the maximum good can be done for the child and the family. In the best interest of the child, your business and my business should become our business.

Summary

Clinical evaluation is a means of assessing a total child. A multidisciplinary approach with free communication between disciplines is suggested as a means of accomplishing this. In this way the team can be used both for initial evaluation and in program planning.

A child-problem oriented approach allows maximum flexibility, both in evaluation and in ongoing program planning, thus avoiding a fixed team or a fixed approach to all children. The child-problem-oriented program not only facilitates use of a multidisciplinary staff, but also helps to cross interdisciplinary barriers.

The Child Study Center program is not the only way to provide a multidisciplinary evaluation to deaf-blind children. Many staff combinations and

different types of facilities could offer a similar program to the deaf-blind child. A cooperative arrangement among programs and services in the community could be established so that a variety of needed personnel is made available on a pre-arranged basis.

However, the results of a national survey indicate that in most programs the information gathered from clinical evaluation is not being used for program planning. This would seem to decrease the usefulness of the information gained, such that the value of obtaining these services might be questioned. One might find it necessary to identify which professionals in a community would be willing to spend the extra time needed to deliver not only their evaluation but also their opinion of the effect of their findings on the child's total

program, including suggestions from within their own field of expertise.

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Table 1
Clinical Service and Degree of Availability

Service	Available routinely	Available on request	Total programs w/service	Percent
General pediatric	51	18	69	95.8
Special pediatric	10	45	55	76.3
Neurological	15	50	65	90.2
Psychological	45	21	66	91.6
Psychiatric	16	40	56	77.7
Ophthalmology	31	39	70	97.2
Otorhinolaryngology	12	43	55	76.3
Orthopedic	12	54	66	91.6
Dental	34	31	65	90.2
Audiology	42	29	71	98.6
Speech pathology	43	24	67	93.0
Language development consultant	36	26	62	86.1
Physical therapy	40	22	62	86.1
Occupational therapy	28	23	51	70.8
Social worker	53	15	68	94.4
Public health, visiting, or school nurse	36	24	60	83.3

Table 2
Availability and Use of Clinical Services
in Primary and Support Categories

Clinical service	Programs w/service	Number of programs, Category E*	Percent of programs, Category E*
Primary			
Occupational therapy	51	35	68.6
Social worker	68	43	63.2
Audiology	71	43	60.5
Physical therapy	62	37	59.6
Psychologist	66	39	59.0
Speech pathologist	67	39	58.2
Nurse	60	34	56.6
Language development specialist	62	33	53.2
Ophthalmologist	70	35	50.0
Support			
Psychiatric	56	28	50.0
Otorhinolaryngology	55	27	49.0
General pediatrics	69	31	44.9
Neurological	65	29	44.5
Orthopedic	66	26	39.3
Dental	65	23	35.3
Special pediatric (cardiology, genetic specialist)	55	10	18.1

*"Category E" is optimal use of clinical information.

Table 3
Use of Clinical Services, by Categories

Clinical services	A	B	C ^a	D	E	Percent in E	Programs w/service
General pediatric	1	16	16	3	31	44.9	69/70
Special pediatric	1	10	8		10	18.1	55/70
Neurological	3	14	9	1	29	44.5	65/70
Psychological	1	5	12	2	39	59.0	66/70
Psychiatric	1	6	7	0	28	50.0	56/70
Ophthalmology	2	15	11	3	35	50.0	70/70
Otorhinolaryngology	4	13	10	0	27	49.0	55/70
Orthopedic	2	14	13	0	26	39.3	66/70
Dental	4	17	12	1	23	35.3	65/70
Audiology	2	10	9	2	43	60.5	71/70
Speech pathology	1	5	15	1	39	58.2	67/70
Language development consultant	0	5	14	1	33	53.2	62/70
Physical therapy	2	6	12	0	37	59.6	62/70
Occupational therapy	2	2	8	1	35	68.6	51/70
Social worker	1	3	11	1	43	63.2	68/70
Public health, visiting nurse, or school nurse	0	3	12	2	34	56.6	60/70

A—Information is filed in the folder and may be unavailable to persons planning the program.

B—information is filed in the folder and is available to persons planning the program. However, no discussion is held with the individual who did the evaluation.

C—Discussion is held between the individual who did the evaluation and the persons planning the program.

D—The clinical information is used routinely in multi-disciplinary staffing sessions, but not necessarily in program planning.

E—The clinical information is used routinely in multi-disciplinary staffing sessions as a tool in program planning.

Sample Team Agreement

This agreement has been drawn up by (teacher's names), (parents' names), and (social worker) as the team concerned with the delivery of services to (child). We realize that the success of this agreement depends upon the cooperation and commitment of all members of the team; only by working together can we fully and appropriately deliver services to (child).

I, the teacher, agree to:

1. Teach four (4) mornings per week and one (1) afternoon (4-5:30) per week.
2. Set up toileting procedures for the preschool, consulting with other team members on other problems as we (team) decide.
3. Give an evaluation at the weekly afternoon meeting on specific tasks of which each member is aware:
The team members will arrange to meet twice monthly to discuss the evaluations in the event all team members are not able to meet at the weekly afternoon session.
4. Meet three (3) times per year in parent-teacher-social worker meeting.

I, the mother, agree to:

1. Participate in one (1) afternoon session per week.
2. Carry out home programs such as toileting.
3. Participate twice monthly in evaluation sessions if it is necessary to meet.
4. Meet three (3) times per year in parent-teacher-social worker meeting.

I, the father, agree to:

1. Support wife in home program. Share toileting responsibilities.
2. Participate twice monthly in evaluation.
3. Meet three (3) times per year in parent-teacher-social worker meeting.

Consequences:

Failure of the teacher to carry out her or his agreement will result in an extra hour of teaching with child.

Failure of the parents to carry out their agreement will result in a two-week probation period, after which time, if the problem is not remedied, services will be discontinued.

Only two (2) probation periods are allowed per year, after which time, if the agreement is not carried out, services will be discontinued.

This agreement can be changed by mutual consent.

I, the social worker, agree to:

Meet as a team member three (3) times a year to assess the child's progress in the program.

Date _____

Teacher _____

Parent _____

Social worker _____

(This is an agreement drawn up for a specific child, with names deleted. Specific contents and items would vary for every child.)

Evaluation Schedule

This is a child with the congenital rubella syndrome. She was born following the rubella epidemic of 1964-65. She was followed closely from the medical standpoint from the newborn period but because of various factors had only intermittent involvement in the preschool program until 1969. After that, attendance was on a regular basis until she progressed into another deaf-blind program.

The schedule below illustrates disciplines that were involved in her care and program planning throughout her stay in the preschool program, aside from the regular preschool staff of teachers, social workers, and physical therapists.

Certain reports which seem to illustrate the flow of the program are also included. They do not represent all of the records kept on this child during her stay in the educational program. Ongoing medical evaluations in cardiology, pediatrics, and neurology (for seizures) were also continued.

Date and Event

3-27-65	Hospital discharge summary following initial team evaluation (pediatrics, pediatric cardiology, child neurology, ophthalmology, infectious disease, and consultation with audiologist). (Birth-date 12-24-64)	11-27-70	Ophthalmology evaluation
6-8-66	Audiology evaluation	12-15-70	Orthopedic evaluation
6-8-67	Audiology evaluation	1-18-71	Audiology evaluation
6-9-67	Otological evaluation	5-11-71	Ophthalmology evaluation
7-24-67	Audiological evaluation	5-17-71	Audiology evaluation
1-22-68	Psychological evaluation	5-24-71	Psychological testing
2-24-69	Psychological evaluation	12-15-71	Audiology evaluation
3-17-69	Medical follow-up	3-14-72	Orthopedic evaluation
7-1-70	Hearing-aid evaluation	3-20-72	Ophthalmology evaluation
11-17-70	Staffing; discussion of plans for following year	6-28-72	Ophthalmology (spectacle evaluation)
		11-9-72	Ophthalmology evaluation
		1973	Final staffing for further placement

Social Work
Progress Notes
June 30, 1969

Re: Nina Thompson

1. A reevaluation by the ophthalmologist was done on May 19, 1969. On the same day the hearing aid setting was checked at the Speech and Hearing Clinic.
2. Nina uses her hearing aid constantly. However, her only response to speech is when mother holds her face close to hers and mouths "no."
3. On Tuesdays and Thursdays Nina continues to go to the Cerebral Palsy Sheltered Day Care Center. She is transported there by one of the workers. The mother reported that she felt that Nina was socializing there. However, she would prefer the Rubella Nursery to be a daily morning session so that Nina might come just to that.
4. Mrs. Thompson found a day care mother, near the place where she works, to care for Nina on Mondays, Wednesdays, and Fridays so that she could be brought to the Rubella Nursery. She entered the nursery on May 12, 1969.
5. We have not begun to talk with Mrs. Thompson about residential placement for Nina because all available information seems to indicate that she is not eligible for such placement until she is six years of age.
6. Dental care: Mrs. Thompson does not yet have a referral to a dentist for Nina. She has been told about this recommendation and will seek that care.
7. A left shoe medial wedge has been applied. The effects have not been bad, and the mother plans to try one on the right shoe.
8. The Department of Public Welfare is considering having a program for the deaf-blind at the Hissom State School for the Mentally Defective. This program has not yet been put into operation.

Social Worker

Deaf-Blind Preschool Program

Staffing Note

11-17-70

Re: Nina Thompson
Bd: December 24, 1964

Present

Child Development Specialist, Educational Therapist, Psychologists, Speech and Hearing Center Child Development Specialist, Supervising Teacher, Teachers, Social Worker from Deaf-Blind Preschool, _____, M.D.

Staffing was requested by the staff of the Preschool for the Deaf-Blind in order to get some direction on continued education for Nina and to discuss possible plans for next year.

Dr. _____ reported that Nina had been known to the Medical Center since she was a few weeks old because she was one of the babies suffering from the maternal rubella syndrome, with congenital cataracts, profound bilateral hearing loss, heart murmur, and bilateral inguinal hernia. She was operated on successfully for her bilateral inguinal hernia at age eight weeks. Cataract operations were performed on the right eye in 1965 and on the left eye in 1966. She had attended the Rubella Nursery at Child Study Center very infrequently, and from the time she was an infant until the fall of 1969 (age four years, ten months) she was cared for outside the home. Because of the retardation in her muscle development and general hypotonia, the medical impression was that Nina was perhaps one of the most handicapped of the epidemic rubella population, with a tentative prediction that she would eventually need custodial care.

Of concern to the Child Study Center staff in 1965 and 1966 was what was felt to be the rejection of Nina by her parents. The mother had indicated that they were unready for any child.

At the present time the parents seem more interested in and pleased at Nina's performance. They are convinced that she is "intelligent." They favorably impressed the staff of the school on March 3, 1969, in that they fulfilled most of the recommendations made. Nina had been attending the Cerebral Palsy Day Care Center two days a week since about November, 1969, and seemed to have gained in socialization.

Psychological evaluation in January, 1968, showed her to be functioning at the nine-month level, but in June, 1968, she had advanced to a fourteen-month level, or five month's progress in five month's time. But by January, 1969, she was felt to be functioning at a twenty-four-month level in selected items, and thus to have made a 10 to 14 month gain in about seven month's time. Recommendations included schooling at the Preschool for the Deaf-Blind, reevaluation by the ophthalmologist, reevaluation of her hearing aid, dental care, remedial shoes, and perhaps eventual placement in a state school—hopefully one specializing in the deaf-blind, rather than one for the mentally retarded.

History in Preschool

From May, 1969, to July, 1969, Nina was seen at the preschool three times per week for one hour each session. At that time she was walking with minimal support, giving the impression that she was more frightened of her position in space than of needing the support to walk. When not given support, she would walk on her knees, with the lower half of her legs turned out. Her fine motor movements were better than her gross motor movements, showing a neat pincer grasp, holding objects with the front part of her fingers.

At the time of the close of school in 1969, Nina was functioning at a one-and-a-half-year to two-and-a-half-year level in fine motor skills but at a lower level in gross motor skills. She was communicating at about the seven-month level, with evidence that her receptive skills were somewhat more advanced. During this first year she seemed uninterested in other children, or indeed in people, but to be quite related to objects. She showed some self-stimulating behavior, waving her hand in front of her eyes. She was quite passive, needing to be manipulated to undertake activities.

In the second year, September, 1969, to July, 1970, she came to the preschool daily for an hour each day. Nina, with her submissive, passive ways, appealed to all of the different volunteers who worked with her. She had made a great deal of progress, particularly in the area of gross motor development. She had moved from being preoccupied with self-stimulating behavior to purposeful behavior with the materials. She showed some degree of associative thinking. She had many strengths which were yet to be tapped.

In the year 1970, one person, the teacher, worked with Nina consistently, and this showed that under these circumstances Nina can, indeed, form a relationship from which she can learn. The teacher reported that Nina had made progress in toilet training, walking, in greater aggressiveness and definiteness in various activities, and in showing some auditory awareness. She was functioning exceedingly well with the limited vision she had. She had learned to put on her coat, to take off and put on her own socks and shoes, although she hadn't yet learned to tie her shoes. She was able to get her milk from the kitchen, place her napkin, pour her milk, spread peanut butter, and clean up the table. She enjoyed many foods and used spoon and fork well.

Nina seemed to know when she had completed a task satisfactorily, refusing to repeat the task. She became more amenable to trying new tasks and new foods. The teacher's opinion was that Nina had begun to make her own decisions about activities she would like to carry out, the times she wants to urinate, and the order in which she wants to do things.

Home Situation

The mother reported that Nina would perform in the preschool but would not perform at home. Thus, Nina can remain dry and urinate in the toilet at the preschool and at the Child Development Center but refuses to urinate in the toilet at home for her mother. She continues to soil, and her mother cannot figure out what schedule she is on for defecation.

Many instances of Nina's awareness and ability to learn were given, for example, her interest in money, her knowledge that one uses money from Dad's wallet when one goes to the store, and her recognition of the corner her parents have to turn to go home when they are driving. However, when there is a change in her routine, she expresses her annoyance by screaming. She resists her mother's requests by going limp and getting what the mother calls "spaghetti legs."

Discussion centered around educational placement for Nina. In spite of the progress she had made in the preschool for the deaf-blind, she still functions like an extremely retarded, passive, almost immobile youngster in environments not familiar to her, for example, at the Center where she was retested in the summer of 1970. At home she spends a good deal of her time standing on her head with her legs resting on the bed. Her sleep habits are very disturbed. This is a fairly new development. In the fall of 1970, she woke up one night, screaming, apparently with a night terror. The parents took her into their bed to comfort her, and although she doesn't scream anymore, she gets up during the night and either plays or gets into the parents' bed.

Confrontation by Dr. (psychologist) of the mother and her still ambivalent feelings about Nina was suggested. This seems to the social worker to be contraindicated since the mother has not asked for this kind of consultation but is using the preschool to the best of her ability, fulfilling, insofar as she is able, school recommendations.

Recommendations were to continue Nina in the preschool, with teachers continuing as they had been this year, with the possibility of either schooling by the Oklahoma City Public Schools next year or at another center or in some residential school.

M.D.

Child Study Center

Midterm Summary Report

September-December, 1970.

Re: Nina Thompson
Bd: 12-24-64

Motor Development

Nina has developed a much more aggressive walk. She still walks with some pronation and imbalance, but she walks with a definiteness that was not there before. She has corrective shoes that help greatly. She is able to pick up materials from the table, get up from her chair, cross the room, and place the materials on the correct shelf. She is able to bend over from a standing position to pick up objects from the floor without losing her balance.

Nina is much more secure on the stairs and alternates when going up and down. She seems to place her feet at a straighter angle on the stairs than when she crosses the room.

We have her working barefoot on the balance beam and in certain exercises that have been recommended by the physical therapists. She pronates less on the balance beam, walking across sideways and also balancing herself sideways for a brief second.

Nina pulls herself up from a squat position with the aid of a pole held by the teacher. She then lets herself down with no fear of the space behind her.

She finds a chair behind her easily and sits with very little slump. Interestingly, when she sits in the rocker to listen to musical records, her position is much straighter and she puts her feet on the floor and rocks herself. She bends over from a sitting position in her chair to retrieve fallen objects without losing balance. When she sits on the floor, she has begun to place her feet crossed before her rather than in the chicken wing position she formerly assumed.

Nina is able to catch a large ball when she is sitting down and return it by tossing or rolling it. She can kick the ball, follow it, and kick it again. She tosses a bean bag into a bucket at a distance of two and a half feet and rarely misses.

Nina has a firmer grasp on brushes, magic markers, spoons, and other materials, holding them where they are meant to be held instead of the tip as she had. She uses the brush and marker with firm, definite strokes but has not yet developed beyond vertical, horizontal, and diagonal strokes. She is able to hold the training scissors with the teacher so that she can cut. She applies paste but does not yet realize that the paper must be applied paste side down.

Nina's eye-hand coordination is very good. She passes a needle through a small hole, grasps small objects, and places them in limited areas with ease.

We have noticed the self-stimulation lessen considerably. When Nina is listening to a record or is involved in painting, and so forth, she exhibits almost no self-stimulation. At these times her eyes focus well and with less nystagmus.

In September she seemed to have little preference as to handedness, but a definite preference for her left hand seems to be emerging.

Language Development

The audiologist observed that Nina's hearing aid was effective in enabling her to hear the spoken word. We feel she might be responding to words such as "light," "soap," and "off," but we are uncertain because we might be giving her signs at the time we are vocalizing.

We have used musical records to encourage Nina's auditory awareness. She listens intently and has a long attention span in this particular activity.

Nina responds very well to the sound board. After about one week's work, she realized the effect of her vocalization on the light and on the sound board. She has explored and produced all manner of phonations on this equipment. She clicks, blows, verbalizes, and taps it against her chin. She enjoys playing the drum, cymbals, and xylophone into the microphone. We covered the light, and the headset is of sufficient interest to keep her involved.

She responds to the voice signal (bah, bah) or to the ball signal in placing doughnuts on the tower. We have been working with the words "ball" and "shoe," using the objects, to see if she is receptively cognitive. We have not had a definite response here as yet.

Adaptive Behavior

Dr. _____, the consulting ophthalmologist, observed that Nina did have limited vision but was functioning exceedingly well with the vision she has. He also felt that whatever manner she adopted to see should be accepted. At times, she puts objects very close to her glasses; at other times, she uses a sideways vision.

Nina is very adept at remembering objects that she has seen and their placement; for example, when she is matching pictures with objects, she will remember that the picture of the tomato is over to the side and will not even look in that direction but merely puts the tomato there.

Her classification and matching abilities seem to be progressing well. She is able to sort colors; monies such as dimes and nickels; knives, forks, and spoons; and so forth. She is able to match objects to pictures, being very careful to get the object in the same position as the picture, even to turning the tomato soup can upright.

When using the circle drawer, she takes the forms out and replaces them correctly without any kind of exploration.

Nina distinguishes and sorts sizes, shapes, and colors well. She also seems to recognize sequences. When she was stringing an ornament for the Christmas tree, she placed the straws and papers on the string in the correct sequence with no help. When using magic markers, she will use each one in turn, not repeating any until all are used. She also puts each cap on carefully and replaces the marker in the container.

She is extremely interested in cause and effect. She enjoys cutting paper, blowing out a candle, and pasting paper. She learns very quickly from demonstration. After one demonstration of the use of the stapler, she was able to use it herself.

Personal Social Behavior

Nina is now very aware of other adults in the room. They even seem to distract her. Recently she has shown an interest in the activities of the other children, trying once or twice to play alongside.

She is able to put on her own coat and zip it if it is placed on the floor before her. She can take off and put on her own shoes and socks, being very careful to tuck her socks into her shoes each time. She is now showing great interest in the laces but as yet has not mastered any part of this. She does prepare herself for the toilet, lifting the seat, taking down her pants, flushing, washing, and drying her hands.

At lunch time Nina takes the pitcher to the kitchen, gets the milk from the refrigerator (with no help) and carries the pitcher of milk back into the room. She places her napkin, pours her milk, spreads peanut butter, and cleans up the table. She enjoys many foods, and uses the spoon and fork well.

Following are certain behaviors I feel are important:

When Nina has completed a task satisfactorily, she does not want to repeat it and is very adamant about not repeating it.

When she is offered a food or task with which she is not familiar, she might try to push it away, but if it is left there and she is encouraged, she will usually make an attempt.

She is also showing definite signs of recognizing her own autonomy. She has begun to make her own decisions about activities she would like to carry out, the times she wants to urinate, and the order in which she wants to do things.

Teacher

Psychologist's Report

May 24, 1971

Re: Nina Thompson

Bd: 12-24-64

Age: Six years, seven months

Referral

Nina was referred for psychological evaluation by the staff of the Deaf-Blind Preschool for assessment of her current level of intellectual functioning and for determination of appropriate school placement.

Evaluation

Due to the multiple nature of Nina's difficulties, standardized testing procedures were not considered feasible. The evaluation was conducted within the nursery, in the presence of onlookers (including her teacher), and in three separate sessions. During the second session, it became apparent that she seemed more motivated to perform the tasks without the support of her teacher; consequently, the last session was administered under regular, standardized conditions with Nina responding favorably to the situation. However, the results of this evaluation are considered only a gross estimate of her present intellectual capacity.

The results of the *Leiter* indicate nonverbal intellectual functioning within the borderline retarded range (IQ score: 74). This test characteristically runs 5-10 points lower than other measures of intelligence, i.e., the *WISC*.

Nina's basal age was at the three-year, six-month level, and the highest subtest passed was at the five-year level.

Although Nina is certainly not functioning at age level, neither is she severely retarded, at least with regard to nonverbal intelligence.

On more than one occasion, her approach to task execution demonstrated the capacity for compensatory behavior which may facilitate the further development of her intellectual potential. For example, she consistently checked her work for accuracy, correcting her perceptible mistakes. Her cognitive approach to the tasks at the four- and five-year levels is considered precocious for that chronological age, and most of the unsuccessfully completed tasks were failed by a small margin. As the ceiling items of the *Leiter* were reached, Nina instigated diversionary maneuvers, suggesting an awareness of her inability to complete the more difficult tasks and indicative of self-esteem protection.

In view of her physical difficulties and despite methodically slow handling of the test materials, Nina's fine motor coordination appears to be fairly well developed. However, she displays a weakened physical capacity, tiring easily and requiring several breaks from test administration, particularly in the initial two-hour session. Her laborious and involved approach to testing probably accounted for much of this drain on her physical energy.

Thus, while Nina is severely handicapped auditorily and to a lesser degree visually, she is making good compensatory use of the slight potential she has. Further, when one considers the multiplicity of her anomalies and the rapid progress she has made in the deaf-blind preschool nursery the past six months, the potential for nonverbal intellectual functioning within the normal range is quite probable. However, in spite of this nonverbal intellectual potential, it also seems likely that Nina's receptive and expressive language deficit will have a significant limiting effect on her overall educational and, perhaps, social progress.

A residential school placement would likely be most appropriate for Nina. The program of the school should stress language stimulation as well as the development and use of nonverbal communication. This kind of situation will probably be of considerable benefit in enhancing her development.

Psychologist

Audiologist's Report

12-15-71

Re: Nina Thompson

Nina conditioned rather easily to pure-tone air conduction testing.

Prior to this time, hearing test results suggested that she may have been responsive only to vibratory sensations at the ear. The results of the present test demonstrate that hearing sensitivity is present through 2000 Hertz bilaterally. It is unlikely that sensitivity to a 2000 Hertz signal is mediated by vibratory sensation.

Copy of audiogram is attached.

Audiologist

Physical Therapy Note

December 31, 1971

Re: Nina Thompson

Nina was very unhappy with her new shoes until she got used to them. After one month they looked like she had worn them for at least six months.

Balancing activities have progressed very well through the use of a small teeter board. She can balance momentarily from side to side and is beginning to show signs of parachute reflex.

For the first time Nina is becoming aware of her body and is momentarily folding her arms and holding this position in maintaining of sitting balance and in activities of forward trunk flexion. With some assistance she is beginning to do active sit-ups and hold her chin tucked on her chest as she comes up to a sitting position.

Some active jumping up and down can be elicited for very short periods. Active neck and back extension are done for the first time by having Nina lie prone on the teeter board and raise her head and shoulders to follow the beam of a flashlight.

We are beginning to get momentary stance on one leg, but she has a long way to go to balance freely on one leg.

We have better success in our attempts to stretch hip flexors, knee flexors, and evertors of the foot.

While it is difficult to know just how much she can see, the following behavior occurred recently: After blowing a large bubble in her pipe, it fell to the floor. Nina looked down at the bubble, and without bending over stamped it out with her foot.

Nina is becoming more independent each day. She can now put on and take off most of her clothes and eat without assistance, and she is beginning to go to the bathroom without assistance.

R.P.T.

Ophthalmology Report

3-20-72

Re: Nina Thompson

Nina is a seven-year-old, white female with congenital rubella syndrome with low vision and hearing.

External Exam

Bilateral microphthalmus

Coarse horizontal nystagmus

Left Hypertropia approximately 20°

Right pupil 1½ mm, left pupil 1 mm slightly peaked

Small capsular strand in pupil OD

Ophthal

Red reflex in both eyes.

Nina is said to be able to materialize small objects 1½ to 2 inches in height.

Impression

Nina has apparently had good results from cataract surgery. She uses her right eye primarily.

_____. M.D.

Ophthalmologist

Physical Therapy

May 11, 1972

Re: Nina Thompson

Nina is becoming more aware of her environment and is interacting a little more with people. In the past month she has learned to jump in response to a tactile stimulation and is beginning to walk unassisted (but very slowly and with apprehension) up the steep steps in front of the Study Center.

Emphasis has been placed this month on trying to speed up all activities and to keep her from lying on the floor as much as possible. She is just beginning to show signs of sitting on a chair instead of always lying down when not stimulated.

New shoes have been bought. She has adjusted much better to these new shoes than the ones she had previously. They have some changes in the wedging, which is helping her to walk with less outward rotation of the legs and eversion of the feet. Since she seems to be more willing to stay upright, we hope that her behavior in this area will show even greater improvement.

The parents seem to be doing a good job in the home with the range of motion exercises that were taught to them. Nina is holding ground in joint motion, but this needs to be rechecked from time to time with the parents.

_____ RPT/OTR

Ophthalmologist's Report

June 28, 1972

Re: Nina Thompson

The patient's parents were advised that surgery might help the vision in her left eye. The ophthalmologist suggested that they might get another opinion.

On my examination several months ago, I noted that the left eye was turned up and that the right eye appeared dominant.

The chances of obtaining a useful left eye after surgery are guarded. There is, however, no chance of the eye becoming useful if surgery is not done. This was explained to the parents.

I will consult with Dr. _____ this week and notify (social worker) of any change of opinion.

Ophthalmologist M.D.

Ophthalmologist's Report

November 9, 1972

Re: Nina Thompson

At my last examination of this patient I advised further surgery on the left eye. This was performed several months ago. She has apparently been unable to see as well without her glasses recently as she had been in the past. She used to be without her glasses almost constantly but recently has used them much more faithfully.

She is able to follow a light or a 2-centimeter yellow ball with either eye. Nystagmus is greater in the left eye than in the right eye on alternate occlusions.

The pupillary spaces are clean in both eyes.

I would speculate that when Nina was not wearing her glasses, she had adjusted to the blurred image she was seeing. As she began wearing her glasses more, she began to rely more on the clear image and was less able to get along without her glasses.

Ophthalmologist consultant M.D.

Final Summary Report
September, 1972–October, 1972

Re: Nina Thompson
Bd: 12-24-64

Gross Motor Development

Nina's progress has been very significant. In addition to a quicker, more stable walk, she has gained confidence in her ability. She steps up one or two steps without any assistance, even a cane. She can step over objects on the floor. She can step up onto the walking board and down with no help. With a cane she is able to walk anywhere, up and down stairs or over rough ground. Inside she climbs onto equipment readily and enjoys doing so. She can hang by her arms or legs or both. She is adept at rolling, creeping on the walking board, and crawling under it. She also turns somersaults well and balances herself well enough to stand on her head. She is not yet confident in walking across the walking board without the cane, but she does so with the aid of the cane. With the cane she can also step over objects a foot high. She walks backward and sideways and up or down a hill.

On the playground Nina uses the swing, slide, teeter-totter, jungle gym, and tricycle. She climbs up into a tree with the aid of a ladder and comes down again. She is able to manipulate roller skates so she can get from one place to another outside on the sidewalk.

Nina has been able to help in the schoolroom. She picks up and carries a chair. She carries the large trash bag out, puts it into the barrel, and covers it. She takes the pitcher out, fills it with water, and carries it back.

During the summer swim program, Nina displayed more initiative in the water than I have seen anywhere. She throws the ball into the water and retrieves it. She throws objects into the water and goes underwater to get them. With very little help she can lie on her back to float. She jumps from the side of the pool into the water. She puts her head under or sits on the bottom of the pool until we count "four," and comes up laughing with no coughing or sputtering.

Fine Motor Development

Nina has shown decided growth here also. She uses rubber bands and clothes pins with a good pincer grasp. She is able to paste well and uses crayons with a definite, heavy stroke. She does not have the control to follow small patterns with the crayon; however, she is able to follow large simple patterns, such as a 6-inch "T," "O," or "V." She does use a large definite stroke with crayon or paint. She can make circular, vertical, and horizontal movements. She has gone from a stage in which she wanted only to make small dots to this stage of large, bright movement. She experiments with all the colors—not repeating colors but careful to use every color.

Nina is able to use a knife to spread butter or to cut soft foods. She uses an egg beater well, pours from a pitcher or small carton, pours from a bottle to a spoon, and uses a bowl scraper very effectively.

She opens and closes jars and tubes—paste and toothpaste—with no help.

Nina does not yet cut with scissors. She does not have the fine motor control necessary for that task. She is not able to tie her shoe laces yet, although she does lace a wooden shoe.

Language Development

Nina seemed to become aware of sound with training. We have used both the auditory trainer and her hearing aid in our daily sessions.

Stimulation with auditory trainer and hearing aid: She now enjoys the xylophone, playing definite patterns of rhythm and going from very soft to loud. She uses the buzzer board and drum in the same way, experimenting with sound patterns.

Awareness with auditory trainer and hearing aid: Nina has been able to hear the bell, the drum, and the shaker when the auditory trainer master control has been turned down to "3." We began with the control at "8" and with increased signs of awareness, worked down to "3." She responds to voice on both the trainer and hearing aid.

Discrimination: Nina is able to discriminate between the drum, shaker, and bell on levels of "8" down to "3."

We have worked on word discrimination, and we feel that Nina is able to discriminate between the words "shoe" and "ball" on the auditory trainer. This has not been totally consistent but has occurred frequently enough for us to feel she is able to hear the difference. We did this with pictures and blocks.

Sound production: Nina is able to produce the *ah* sound on request and will reproduce the number of *ah* sounds that has been given to her. She also can produce *b*, *p*, and *m* sounds with tactile help.

Manual Language

Receptive: Nine can understand over 100 signs and also reads combinations such as *you go to the toilet; you put on your coat; you put this away; you go bring water; it is time to eat; Nina, tell me how many; Nina, bring me car; and Nina, go outside and play on the swing.*

She understands the sign which means her name (an N sign). Nina also understands numbers "1" through "5" and can bring the correct number symbol on request.

Expressive: Nina is able to use combinations of signs as well as single signs. At the end of the report is a list of signs she uses both receptively and expressively.

Adaptive Behavior

Nina is now able to come into the room, go to her shelf, select her materials, and sit down to work with them. She is able to work through four or five worksheets without help from anyone. She then puts her work and materials back on the shelf.

If we are working on signs, written language, and so forth, she attends well for as long as a half-hour.

Response to Structure

Nina picks up a structured activity quickly. She seems happy in knowing exactly what her schedule is. After internalizing the structure of an activity, she is able to carry it through unaided. Activities she is able to complete are:

- | | |
|----------------------|--|
| 1. Preparing pudding | 6. Blowing bubbles |
| 2. Preparing eggnog | 7. Taking out the trash |
| 3. Making Jello | 8. Toileting, washing, and so forth |
| 4. Making cookies | 9. Dressing and undressing |
| 5. Washing the table | 10. Shopping for fruits and vegetables |

Initiative Behavior

Nina is weak in initiative behavior; however, she has grown in her ability to go from one activity to another without collapsing into the fetal position. If her activities are structured, she is able to continue from one to another without help. However, if she is uncertain as to what to do, she may go down to the floor. She also still needs encouragement, in free time, to get activity materials with which to occupy herself.

Outside she does go from one activity to another. She will swing, ride the tricycle, or climb without encouragement.

Response to Sequential Activities

As I mentioned earlier, Nina understands and responds to sequenced activities. She quickly learned how to make pudding and eggnog. In her toileting and dressing, she keeps a definite order of events. When she has a four-bead pattern to follow or a four-block sequence, she can repeat it after she has studied the patterns and they have been covered.

In the recognition of the printed words, Nina can arrange the letters of several words in the correct order.

Self-Stimulation

Nina still flicks. However, this seems to occur when she is excited or happy.

Memory

Nina excels here. Her memory for sequencing is very good. She knows where materials belong. Her memory for the printed word, colors, shapes, pictures, and objects is remarkable. She can look at a word

such as *ball*, walk across the room, and select the correct object from a group of four or five. She does the same using signs. She will look at the pictures of four objects, cross the room, and select the pictures of those four objects from a larger group.

Personal Social Development

Nina enjoys being with and playing with adults. However, while she is beginning to show an interest in other children and often walks up to see what they are doing, she does not seek them out to play.

She has been seen to lash out at a child who takes her toys or to push a child who is annoying her.

The area in which real growth has occurred is in separating from her parents. Previously she had great difficulty in working or concentrating if her parents were in the schoolroom; she wanted to go to them. However, she is now able to continue her work and go to them after she has finished.

She will work with any adult. She adjusts easily. However, she reads people quickly and will produce only enough to get by. She will ask to be carried if she feels that the person will give in. She will not urinate if she thinks the adult will not insist. Nina also will procrastinate if she thinks she cannot do a task.

Visual Behavior

Nina overcompensates (the ophthalmologist feels). Her eyes are one third smaller than the normal eye. She has nystagmus and has had several cataract operations. Her vision has been judged 10/400; however, she has functional vision. She sees well enough to move around the environment. She can see one and a half-inch print on the blackboard at about four feet distance. She distinguishes three-fourths-inch print and at one time was able to match the words of a bulletin typewriter. She can work with some puzzle pieces on the floor and some on the table. She is able to distinguish the matching pieces easily. She can do the same with matching words or pictures. She is able to distinguish between persons and between objects on small photographs. She is able to tell us, by signs, what is happening in the picture.

If Nina feels she does not need to use her eyes, she will close them. However, if she knows she needs them, she will make an effort to keep them open and focus. For instance, if someone holds her hand as they walk, she closes her eyes as she walks along beside the person. However, if she is given a cane and told to walk by herself, she uses her eyes to focus on the tip of the cane and the ground before her.

She can follow the movement of a candle or a bubble five or six feet away. She can string beads or straws with very small holes. She pours well and stops within an eighth of an inch from the top of the cup. She is able to retrieve small articles when she drops them, even if they roll away.

Before Nina began to wear her new glasses, she seemed to adjust in a few days if she broke her other glasses. She was able to function without them. However, she now seems to be very dependent on these glasses and works much better with them on. She takes care of them and puts them into the case when she takes them off.

Self-Help Skills

Nina has achieved certain self-help skills.

Dressing

Nina is able to dress and undress herself. At times she does confuse front and back. I had asked her mother to identify the fronts of her clothing with a mark. When Nina looks at the clothing she is putting on, she does a much better job, quicker and easier than when she isn't focusing.

She can button and unbutton large buttons. She is not yet able to manage small ones.

Nina does not tie her shoe laces. She puts the laces in the shoe but has not mastered tying.

Eating

Nina eats well and a great variety of foods. She handles the fork and spoon well. She can spread butter, and she can use a knife to cut soft foods like bananas. She doesn't cut meats or hard foods. She pours well and uses a napkin and cup well. After she is finished, she cleans up her dishes, washes and dries the table, and takes the large garbage bag out to the garbage can. She also carpet sweeps the floor.

Toileting

Nina responds to the R.R. restroom sign. She takes care of herself, flushes the toilet and washes and dries her hands. She has been dry except for infrequent accidents. However, she does not like to touch herself. We have been working on this, using sticky substances and having her wash herself with a sponge.

We have not had any experience with BMs during school. Nina's mother reports that she has her sit on the toilet every morning but that she does not have a BM then. However, when she had her surgery last summer and I visited her in the hospital in the evening, she had a BM very easily on the toilet. So I don't feel there will be much of a problem here.

Practical Life Tasks

Nina has been able to accomplish certain practical life tasks. After going through these tasks with much help from the teacher, she was gradually able to lessen her dependence on the teacher and carry out the task from start to finish with no help.

Nina would have a banana, a knife, a plate, a cutting board, and a paper towel. She would slice the banana on the cutting board, put it on the plate, and eat it with a fork. After that she threw away the towel with the peelings and took her dishes out to wash them in the sink.

The materials for instant pudding included the package of pudding, a bowl, a carton of milk, an egg beater, a dish, and a spoon on the tray. Nina opened the pudding and the milk and poured them into the bowl. She used the egg beater to beat the mixture until it was thick in consistency. Here she was making a judgment and decision. She would scoop it from the bowl into her dish, eat it with a spoon, throw away the cartons, and take her dishes out to wash them. She would bring the dishes back and put them away on the shelves.

In making eggnog, Nina followed the same procedure as with the pudding, but this procedure was more complex. She had to measure sugar and vanilla with a spoon. She also broke the egg into the bowl. However, she was able to carry through with minimal help.

Personal Relationships

Nina accepts any adult readily. However, she reads people very well, performing at the level they expect of her.

At the Day Care Center, the teachers have been asking a great deal more of Nina. They are using signs with her. She responds well. She goes to the toilet, dresses herself, and works at the table with the other children. We have sent seat work to the Day Care Center, and Nina has been completing these sheets and doing them well.

In Nina's relationship to her parents, there is a decided difference. Her parents have expected very little of her. They carry her much of the time, although they have been asked not to. They have not been able to carry through on tasks she is expected to do at home. At home, she throws her glasses and her toys. She fusses and asks to be carried. She will not cooperate in toileting. Her father feels they have not been consistent and have not persevered.

However, when Nina began to work on her reading book and began to recognize printed words and numbers, her father and mother worked very hard and consistently with her. They felt very encouraged with her progress in language work. They did not work on manual language with her except for a few signs.

Final Impression

In my opinion if Nina's parents had been able to carry through with suggestions at home, she would have shown greater progress than she has.

Teacher
Deaf-Blind Home Program
Child Study Center

Signs Nina knows

again
apple
bad
ball
banana
bird
break
bring
brush hair
brush teeth
buy
candy
car
cat
climb
coat
coke
cold
come
cookie
drink
dry
eat
egg
father
finish
fork

go
good
good-bye
good morning
gum
hat
I
in
jump
knife
lemon
look
me
milk
mistake
mittens
mother
more
no
now
number
off
on
open
orange
orange juice
out

over
pants
play
pour
push
put
roller skate
run
same
see
shoes
show
shut
sit
slide
sleep
socks
sour
stop
store
sugar
swim
swing
tell
thank you
throw
toy

tricycle
turn
under
up
vanilla
walk
wash
watch
water
wet
what
which
word
yet

Colors Nina knows

one
two
three
four
five

Numbers Nina knows

red
blue
yellow
orange

PARENT SURVEY

Please respond to the following items on a scale from one to five, with five being the highest possible rating:

1. The Child Study Center Staff is effectively helping my child in the following areas:

A. Psychomotor development (fine and gross motor coordination)	1	2	3	4	5
B. Language development	1	2	3	4	5
C. Self-help skills (dressing, feeding, toileting)	1	2	3	4	5
D. Adaptive behavior	1	2	3	4	5
E. Social and emotional development	1	2	3	4	5
F. Perceptual learning skills and concepts	1	2	3	4	5
G. Individually tailored educational curriculum	1	2	3	4	5
2. The Child Study Center Staff is effectively helping us, as parents or foster parents, in the following areas:

A. Implementation of team agreement	1	2	3	4	5
B. Adjustment counseling	1	2	3	4	5
C. Exploration of available educational, social, and medical resources in the community and state for the family	1	2	3	4	5
D. Regular diagnostic services in all necessary areas	1	2	3	4	5
E. Providing consultative services	1	2	3	4	5
F. Providing transportation to and from the Child Study Center for our child	1	2	3	4	5
G. Focusing on concerns expressed by teachers and parents	1	2	3	4	5
H. Encouraging parental involvement	1	2	3	4	5
3. I would like to see the following services begun or increased at the Child Study Center:
4. Other comments:

Educational Assessment of Deaf-Blind and Auditorily-Visually Impaired Children: A Survey

Nan Robbins

Diagnostician, Department for Deaf-Blind Children, Perkins School for the Blind

The intent of educational programs for deaf-blind children and youths in the United States is to offer services to those individuals who are in need of special, personalized, and individualized service either because they are indeed deaf and blind by sensory definition or because their development is being interfered with due to multiple disabilities, including some degree of visual or auditory impairment.

Variables in the Population

Sensory capacity—degree of sight and hearing—has a bearing on which test materials one can appreciate; one's approach to learning; and, in some ways, one's direction, rate, and ultimate level of development.

The presence or absence of other variables must also be discerned or considered in the process of educational assessment of individuals. The list of identified variables in the population is long and includes the following (Robbins, first 1972 reference; Chess, 1971; Cochran, 1969; Wagner, 1970; Curtis, 1970; Bergstrom, 1971): genetic inheritance; family circumstances such as size, living style, financial circumstances, values, mental health, and child-rearing practices; health, past and present; onset and progress of visual disability or auditory disability, or both; present visual or auditory capacity, or both, aided or unaided; psychoneurological interferences with learning (central nervous system integrity); language-learning capacity; movement disorders; sensitivity and arousal level; personality and temperament; rate of development; age of initiation of sensory aids and educational intervention; appropriateness of the educational intervention to the individual; and physical appearance.

Clearly, all these variables would have a bearing on the educational status of an individual at any given moment and would also influence the educational assessment process, instruments needed, and areas of assessment to be covered. Assessment must be designed to meet the needs of any deaf-blind individual. Libby Wagner (1970) pointed out that the only thing individuals in the deaf-blind population have in common with each other is the fact that at some time "they were believed to have a combined vision and hearing impairment." The deaf-blind encompass all the possible differences among people and more:

Among the deaf-blind there are the intellectually gifted and the dull-witted, the weakly insecure and the ambitiously domineering, the passive and the dynamic, the fearful and the bold... It is all too easy, in a label-minded society, to treat all deaf-blind people as though they belonged to a single category, but this simplistic view fails to take the human equation into account (Salmon, 1970).

Assessment of Educational Programs for the Deaf-Blind

In the offering of services to children classified as deaf-blind, the term "education" has taken on a broader usage and meaning than those generally relating to the school or to the subjects of reading, writing, and arithmetic.

Providing educational and developmental services to many of the rubella deaf-blind children whom we are serving has necessitated a broadening of our definition of education to a great extent. We no longer consider education as being those experiences which are traditionally academic in nature. We consider ourselves an educator when we go to school in the morning and attempt to teach children how to button their shirt or how to brush their teeth, or how to go to the bathroom,

or how to handle a knife or fork. This is education, and this is how it should be, for without this broadened definition there would undoubtedly be many of the children with whom we are now working who would not be eligible for educational services (Hatlen, 1970).

The need for educational assessment of the deaf-blind extends from assessment of sensorimotor development in infancy and early childhood to assessment of the progress of the young deaf-blind adult who requires the services of an interpreter to function in a traditional high school program. Or even, if one so chooses, to the young adult needing education under rehabilitation services or the auditorily-visually impaired fourth grader who has been integrated into the public school program.

Fischer and Teske (1974) view assessment as "an integrated set of diagnostic exams of an individual child." Webster defines *assessment* as an appraisal, an estimation. This implies a judgment, and it implies the discovery of assets and liabilities seen against some theoretical or actual structure of measurement. Hence, one should have a point of view on the psychology of the deaf-blind to identify the basic areas in which assessment is needed, to interpret assessment results, and to describe the deaf-blind child as a learner.

Variables in Educational Assessment

Before beginning a survey of assessment models, tools, approaches, and interpretations with regard to the deaf-blind, one should note that for years there has been controversy in the field of psychometrics as to what kinds of tests or frameworks are appropriate to use to describe children's current knowledge and ability to think. The trend has been away from focusing on test scores per se, which have, erroneously but frequently, been taken to indicate unchangeable characteristics. The move has been toward more descriptive approaches in which an attempt is made to recognize that the child is a learner; is capable of change; and has, at a given time, at least some of the information included in a defined body of desirable information.

Scores, as results obtained from normative assessment tools or standardized tests, are useful for particular purposes, including describing briefly certain facets of a child's current behavior with respect to some describable standard or norm. The difficulty is in knowing whether it is fair to compare the child in question to the normative group, or, if one does, in knowing what the

comparison really means. This becomes a particular problem in the area of education for the deaf-blind, which is inherently heterogeneous and in which individual differences are the basis for grouping. The alternative is to describe the individual's performance capability along some describable continuum, whether this be an outlined curriculum of knowledge or skills, sometimes referred to as criterion-referenced tests rather than normative assessment, or along developmental schedules of normal sequences in learning. Using the latter approach, one hopes to be capable of determining "what a learner can do, regardless of whether he can do it better than another learner" (Ricks, 1971).

Variability exists not only in the choice of assessment tools or techniques but also in the ability of the person conducting the assessment to make objective observations; to interpret the results of the assessment; and to know if, in fact, the child "took the test." In any assessment, factors of place, time, mood, weather, companionship, and health influence behavior. The assessor's role is to be alert to and name those factors that are adversely affecting the behavior of the child at the moment.

Assessment should be based on the information that is needed to describe the deaf-blind child as a learner, followed by a listing of specific questions that are pertinent to the situation of the individual child in question. Presumably, one would then choose normative tests, descriptive approaches, or criterion-referenced tests, whichever would best answer the questions being asked.

Scope of This Survey

This survey is intended to describe the present status of theoretical constructs, tools, techniques, and interpretive knowledge relating directly to the educational assessment of deaf-blind children—to the appraisal of the individual's assets and liabilities; i.e., his or her present status. Several areas of assessment and endeavor relate vitally to educational assessment and to subsequent recommendations or prescriptions for education but are not treated in this presentation:

1. *Home:* What are the individual's family needs? What have been the assets for him or her and the problem areas? What are the family hopes and expectations? What are the needs the family must plan for in the future?

2. *School*: What are the options regarding where instruction might take place? If instruction is on-going, who is the person offering instruction? Who are or will be his or her classmates?
3. *Community*: What resources are available locally? What are the cultural pressures?
4. *Curriculum*: Educational assessment must be related to curriculum, since one must define in what specific ways "mental and moral development are desired before appraising whether they have been achieved or what personal assets and liabilities might be related to achievement."
5. *Sensory assessment*: Clearly, the status of vision and hearing determines or affects the testing instruments to be used, interpretation of test results, and method to be used. Visual and auditory assessment, however, will be treated elsewhere.
6. *Medical, neurological, genetic, and etiological status*: Health and central nervous system integrity affect current learning and longitudinal development. Assessment results in these areas are a vital corollary to interpretation of the description of behavior obtained in the educational assessment and often a vital corollary to choice of remedial techniques. For example, an individual may be easily distracted and inattentive because of emotional distress. Such condition may be alleviated by changes in management. If the condition is the result of seizure activity, medication will serve to change the behavior.

These areas of assessment of deaf-blind children or adults provide the crucial basis for (1) interpretation of the educational assessment data which are gathered; and (2) choice of remedial techniques or plans. One should remember this while surveying educational assessments, models, approaches, tools, and techniques.

The Search for Assessment Models: A Psychology of the Deaf-Blind

What is the effect of partial sensory limitation of vision and hearing on learning, on sensory adjustment, or on development? What is the effect of deaf-blindness?

Compensatory Sensory Adjustment

Myklebust (1956) offers a theoretical structure for understanding and assessing children with dual sensory impairments, based on recognition of three

major systems in the human being, each of which can suffer injury or aberrant development, and each of which must be assessed:

1. The peripheral nervous system offers sensory capacity in hearing and vision as primary senses capable of near and distant reception; touch as the next most vital sense, with some minimal possibility for distant contact through vibratory sources; and taste (gustation) and smell (olfaction) as secondary supplementary senses. Maldevelopment of primary peripheral senses is referred to as deafness, blindness, or hearing impairment.
2. The central nervous system, mechanisms in the central neurological system itself, can malfunction, resulting in aberrant behaviors referred to as brain damage, aphasia, epilepsy, or cerebral palsy.
3. The term *psychological integrity* refers to the observable behaviors resulting from the effect of central nervous system integration of sensory inputs from the peripheral system with the demand for adjustment of the individual to the environment. In assessment one must consider mental ability, emotional development, social maturity, motor functioning, and language development.

Myklebust's assumption, which is based on observation of differences in children with auditory and language disorders, is that "an organism naturally attempts to maintain adequate homeostatic relationships with its environment and that it does so on a self-preservation basis with the best means at its disposal." Simply speaking, a normal deaf child will make a shift in his or her sensory organization to utilize vision for both near and distant contact. Because the deaf child's problems are only with the peripheral auditory system, his or her ways of entertaining himself or herself, the things he or she learns in self-help, his or her social interactions, and his or her performance on visual test items will indicate capability through use of the visual sense. Similarly, according to Myklebust, the deaf-blind child with good psychological integrity but serious impairment of vision and hearing will use his or her intact tactual sense in attempting tasks and dealing with people and his or her senses of smell and taste in a supplementary manner for examination and identification. Children with central nervous system dysfunction do not, then, show the same degree of compensatory sensory shift nor the same adequacy of psychological integrity.

Using this theoretical framework, Myklebust suggested an approach to the assessment of deaf-blind children, using parts of standardized tests of development and intelligence and observations of behavior to determine patterns of adjustment. This theoretical framework was used as a base for development of assessment techniques at Perkins School for the Blind, and it continues to be vital to interpretations of the various behaviors of the population of children. This construct assumes that human beings persist to adjust, even to the serious deprivation of total deaf-blindness, and that the degree of persistence is determined by the adequacy of the integrating system.

The different adjustment patterns are believed to have implications for methods of education. For example, the peripherally injured, totally deaf-blind person for whom one-to-one instruction is offered with language teaching through the Tadoma technique of tactual speechreading and a conversational, natural language approach can, by physical and sensory compensation, readily respond to education. On the other hand, a partially-seeing, hearing-impaired child, who shows an adjustment pattern that indicates areas of lowered psychological integrity, may need methods of teaching in which emphasis is on the sense that functions more adequately, simplification of tasks, and structure to promote focused attention on tasks at hand. This construct assumes that behaviors not due to actual losses of function will be amenable to educational procedures. This view of behavior implies that some adjustment mechanisms may in fact be absent from the central nervous system. Robbins (1971) speculated about the severely communication-defective, congenital rubella children often described as autistic (Chess, 1971; Guldager, 1970), suggesting that since genetically transmitted physical characteristics can result (most obviously mongoloids), genetic programming for certain effective mechanisms may also be missing. Mechanisms suggested as possibly absent in some children were smiling at persons; eye contact; the tendency to cling; the tendency to look for rules or patterns of organization in the environment (in people's actions and in language, for example); the tendency to orient and scan in response to sensory stimuli; and the tendency to imitate observed behavior. The implication is that the absence of such patterns of adjustment has a permanent effect, requiring methods of compensation that are different from those of simply trying to produce the absent behaviors themselves or

trying to improve the overall affective social environment of the child.

Sensory Deprivation: Inadequate Environmental Experience

Whereas Myklebust emphasizes recognition of sensory residual patterns and observation of sensory adjustment patterns, others emphasize the limitations in seeing and hearing as seriously limiting environmental experiences, resulting in retarded development as well as psychological isolation. Massive sensory deprivation, rather than psychological integrity, is cited as having the greatest effect on adaptive behavior, emotional adjustment, and sensorimotor development (Browning, 1974). "It is impossible for either the sense of sight or sense of hearing to assume the developmental burdens of the other." Nevertheless, the child is believed to need to "learn to utilize his or her remaining sensory pathways," to have "opportunities to learn to see and hear, to learn to organize the stimuli from the environment using all the senses."

Bisno (1972), Ashurst (1972), Chess (1971), Tracy (1970), and others cite Piaget's theory of child development during the sensorimotor period in support of this construct. The importance of adequacy of the environment for continued development through the sensorimotor period is emphasized:

Piaget defines intelligence as an ongoing process of organization and adaptation. It is an activity that allows the individual to develop a fixed sequence of "schemata" or behavior patterns through interaction with the environment. The environment provides stimuli which the child must actively assimilate or incorporate in order for his intelligence to develop. This interaction between child and environment is the crucial element in the development of intelligence (Chess, 1971).

The deaf-blind child is seen as unable to progress within the substages of the sensorimotor period due to "the enormous experiential deprivation" resulting from the limitation on input caused by the sensory deficits (Bisno, 1972). Bisno explains that the need to make adjustments to the world is neither perceived nor experienced by the child; therefore, whatever impinges on him or her is assimilated into his or her present patterns of behavior, and developmental fixation is the result. Bisno suggests that there may be central nervous system involvement but that it is impossible to assess maturation of the nervous system because the sensory limitation has isolated the child and arrested developmental change. This theory is

particularly applied to those congenital rubella children who are, at age six or seven or so, still in the sensorimotor stage with autistic behaviors (Ashurst, 1972). The apparent absence of developmental change in some of the congenital-rubella children, in spite of preschool programming, is seen by Ashurst as a result of the fact that intervention was not early enough.

The Piagetian developmental theory focuses assessment techniques away from a pass-fail system on test items and toward description of what strategies the child has available for interaction, for viewing problems, and for solving problems (Tracy, 1970). Since the development of schemas for interaction is believed to be invariant in sequence during the sensorimotor period and since each is seen as prerequisite to the emergence of the next, the assessment structure lends itself to early intervention methods (Guldager, 1970).

Sensory Deprivation: Isolation from Person Contact

Van Dijk (1963, 1964-67, 1965, 1968) discusses the psychological effect of sensorilimitation on the mother-child exchange, emphasizing the isolation that occurs as a result of change in maternal responsiveness to, and actual physical handling of, the child from whom she is alienated by the sensory deficits. Movement is seen as the basis for the young child's establishing a knowledge of self (body), by movement in the world and by movement with people. When normal maternal handling and imitation of motor behaviors do not occur, the child does not develop an organized and unitary ego.

In a later writing (1971) van Dijk seems to be shifting or adding to the maternal-distance factor another factor—that of actual central nervous system difference in the child, which results in a psychoneurological inability to integrate fragments of experience and hence an inability in the child “to perceive the relationship between mother and pleasure.” Because the child therefore does not differentiate between self and nonself, he or she is unable to generalize and unable to imitate. Because of his fragmentation of perception and “lack of comprehension,” he or she wants to keep the world the same, and the often-observed, “rigid, invariant behaviors” ensue.

Van Dijk has projected his theory into an educational plan that focuses on the need to encourage growth of the child's ego-consciousness through “development of body-knowledge.” The educational techniques focus on music and move-

ment—movement in space, movement with a person, and, eventually, imitation of movement and, later, of word.

Guldager (1970) generally shares van Dijk's psychological-effect viewpoint but adds to it a neurological postulate. Referring only to a population of congenital rubella children, she sees the autistic behavior and motor inactivity of the deaf-blind children as due to an isolating interaction of causes: (1) sensory deprivation from birth, resulting in a lack of development of body image and possible consequent distortion of perceptual, cognitive, and motor development; (2) isolation from their family because of their abnormal response, causing the family to ignore them and to not handle them, and creating consequently an even more monotonous environment; (3) central nervous system damage due to the early effects of the virus on neurological growth; (4) frequent early surgery resulting in motor inactivity and additional isolation; and (5) eye surgery in particular possibly adding to regression and withdrawal as a reaction to sudden, increased sensory stimuli. The theory was postulated from this observed behavior in animals.

Guldager postulates a defective reticular formation (after the theory of Prick, 1971), the result of which is that the child does not seek variation in stimuli as does a child with a normal system. Rather, the child “chooses” light-gazing or other repetitive behaviors over searching for arousal experiences. She also postulates central nervous system damage on the basis of the observed perceptual problems; motor difficulties; olfactory and gustatory deficits; inability to chew; mental retardation; and aphasia in certain congenital rubella children. Guldager combined this psychological view with a Piagetian approach to assessment of sensorimotor behaviors and, for the preschool period, built an educational developmental model relating to certain assessed behaviors.

Learned Behaviors

A somewhat different construct is apparent in the viewpoint of Meshcheriakov (1962), who appears to be discussing the totally deaf-blind. He believes that all behaviors are socially learned, including the orientative reflex (a motor response on the part of the child, directed towards a better perception of the object). He states that the deaf-blind child will, if isolated from social teaching of habits by being restricted to a partitioned-off corner of the room, in bed, and so forth, “have no investigative activities” and will have learned

nothing—to “walk, eat, or drink like a human being,” language, or facial expressions, such as smiling when pleased. He states that the “blind and deaf and dumb” child possesses potential for development, but will remain “an invalid” if left to his or her own efforts. Meshcheriakov does not explain what behaviors are present that suggest to him that the individual is capable of change. His theory is related to some educational steps but suggests nothing with respect to assessment. In fact, at least initial assessment is unnecessary since the educational steps are invariant and build a set of specific behaviors. Meshcheriakov's explanations are only very briefly described. Even so, his approach seems to be similar to the approach of the behaviorists, who look for no real explanation of behavior but merely go about changing them by manipulating the environment and by offering occurrences of extrinsic motivation (Hitzing, 1972).

Schematics or Models

The contributions of schematics or models to a theory of development applicable to view the behavior of a wide range of individuals with sensory disabilities are indeed useful in the search for a system. The educational status of any individual, his or her status as a learner, is at any given moment the result of cumulative influences, not of any single cause. A tentative, schematic outline that was used at Perkins and in which are noted aspects of persons and environment that must be considered by observation, by interview, or by test in the search for total description of the learner and for an educational plan is offered in Figure 1, on page 114.

Two models for the assessment of cognitive processes, viewed particularly as they relate to the development of language, are offered in figures 2 and 3 on pages 115 and 116. Hammer (1974) describes an approach organized into four systems of behavior and a hierarchy of processes of organization. The motor-output side of the schema is offered as the area of evidence suggesting that the sensory, perceptual, or conceptual events are happening internally in the child. “As the system builds and becomes intact, there is a collection of these experiences (sensory and perceptual) which is stored and becomes what may be called memory If the process of organization is intact through these levels, it is possible for the person to progress a step further, to the emergence of concept formation in the individual.” Concept formation is defined, in Hammer's discussion, as the ability to call upon sensory, perceptual, and

memory behaviors to initiate or generate new activities, and to influence and act upon the environment. “Concept formation, per se, cannot be observed; concept formation can be measured on the output side ... through ideas, thoughts and language” (Hammer, 1974). This model apparently is derived from that of Wepman. The model offered by Robbins (Robbins, and others, 1970) (Fig. 2), relates to that of Hammer/Wepman but on a less explicit level.

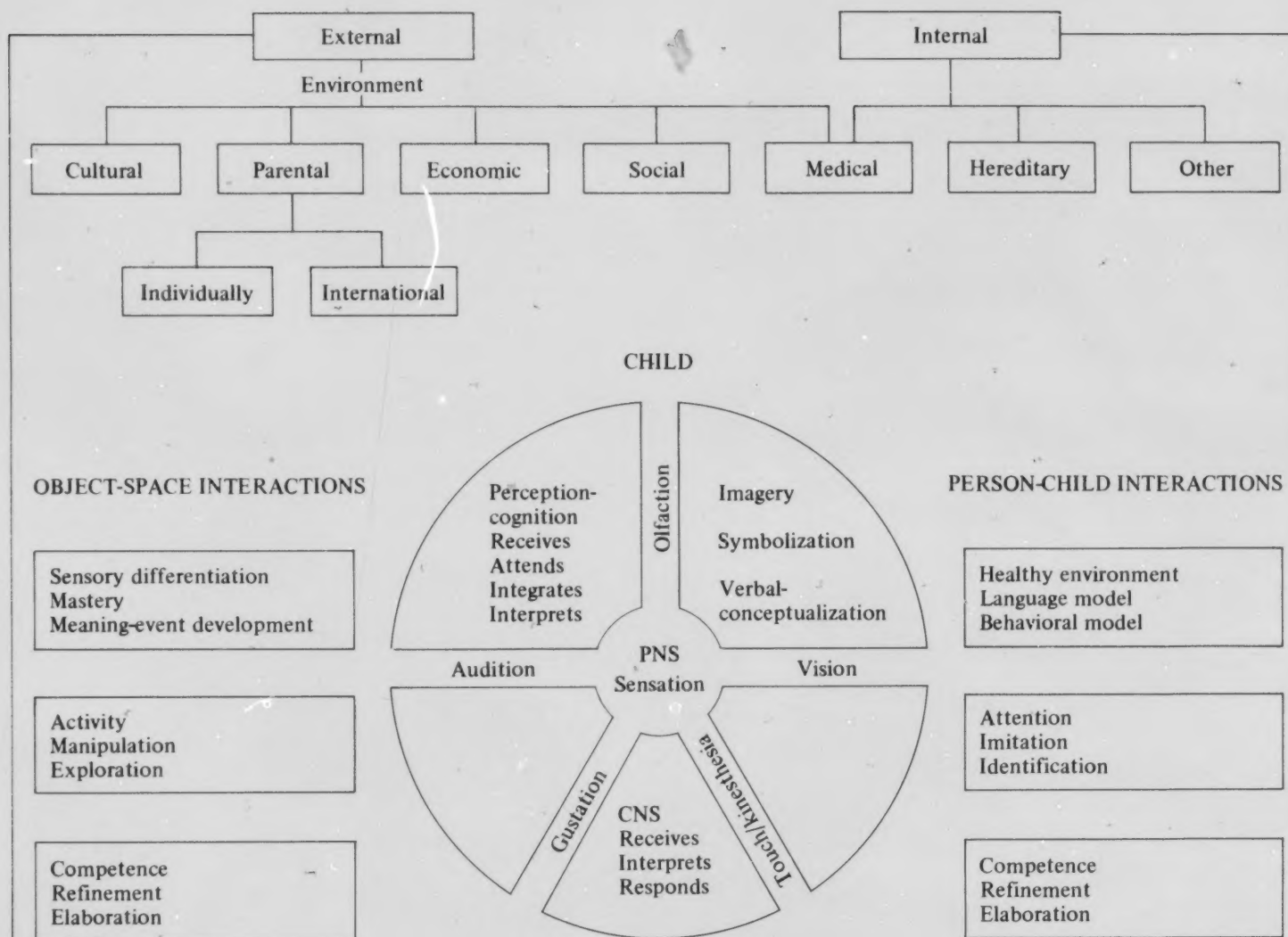
Summary

Those commenting on theories of behavior with respect to the deaf-blind have focused on explaining the autistic and developmentally infantile behaviors of a large number of the congenital rubella population. Their combined efforts recognize the developmentally disabling effects of central nervous system damage, damage to the ego (1) by isolation from people impaired by sensory limitation; (2) by actual physical isolation, as in hospitalization, and by parental rejection responses resulting from the child's initially deviant responsiveness; and (3) by isolation, sensory and physical, from sensory and sensorimotor experiences sufficient to stimulate continual development. Through infant-stimulation programs some of these effects are avoidable; through education of family and child, some are remediable. Some of the effects are, however, presumably permanent limitations. Professionals in the deaf-blind field disagree as to whether it is appropriate to attempt through assessment procedures to differentiate, in the behavior of the individual, that which can be changed by means of stimuli or education and that which is permanent limitation, or whether it is even possible to do so. It is a fact that many parents ask, and more think to themselves, “What will he be able to do when he is twenty?”

Myklebust and Meshcheriakov were theorizing from populations that included some children who were not congenital rubella children. Therefore, they contribute another important part to the development of a psychology of the total deaf-blind population: the idea of the importance of social learning, through visual imitation and through language, for humanization and acculturation, and the idea of the persistence of the human being to learn and to compensate for severe deprivations if offered a minimal amount of personal attention and physical possibility in his or her environment.

Any psychology or assessment model for the deaf-blind must recognize the possible influence of

Fig. 1. Impediments to normal language development



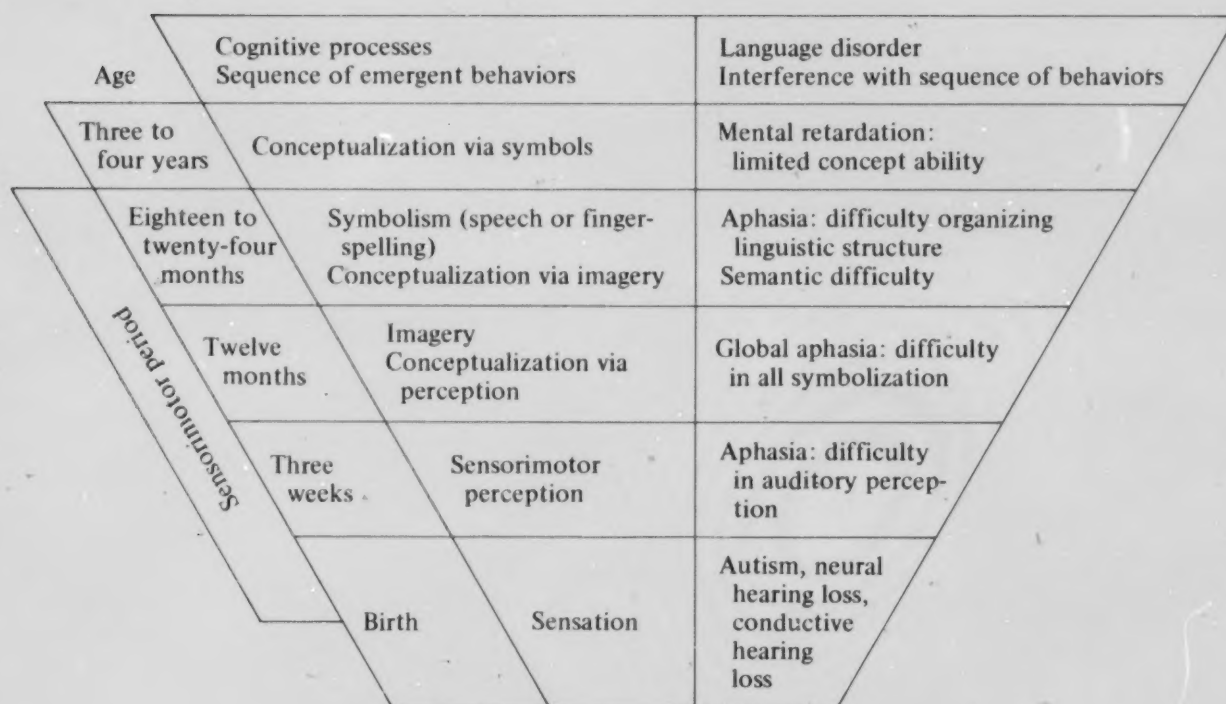


Fig. 2. Language disorders

history (genetic and cultural effects), integrity of body and brain, different sensory capacities, physical and chemical changes accompanying physical growth, different child-rearing practices, and different environmental richness or poverty on the development of the individual in question.

Some General Assessment Issues

During the past ten years, three trends have developed in educational assessments:

1. A multidisciplinary team of specialists, including medical personnel, who work separately, leaving coordination of impressions and recommendations to one member of the team (Curtis and Donlon, 1969). (The team may or may not include the parent as an active member.)
2. An interdisciplinary approach, using a number of specialists but arranging for actual in-person exchange between the specialists and even mutual, simultaneous observation of a child (Fischer and Teske, 1974; Robbins, 1975).
3. Use of a developmental checklist by the teacher or observer to structure and organize

observations (Stillman, 1974). (Stillman favors the teacher as observer since such provides for greater flexibility in time and in variety of situations.)

The tendency seems to be to use the team approach for initial assessment or for training demonstrations but to rely on teachers for ongoing, periodic, educational assessments, in particular to measure student progress.

The multidisciplinary team, usually organized in a medical center, consists of specialists in fields such as ophthalmology, pediatrics, speech pathology, audiology, occupational therapy, physical therapy, and social service. The specialists see deaf-blind children as a relatively small facet of their total case load. The perspective may be helpful. A somewhat different viewpoint is found among some interdisciplinary teams (Robbins, 1975) that work more exclusively with deaf-blind populations and whose members each represent more than one area of specialty, all focused toward education. Most interdisciplinary or multidisciplinary teams use a person whose title is, or who fills the role of, education specialist in the field of deaf-blind education. This person often acts as

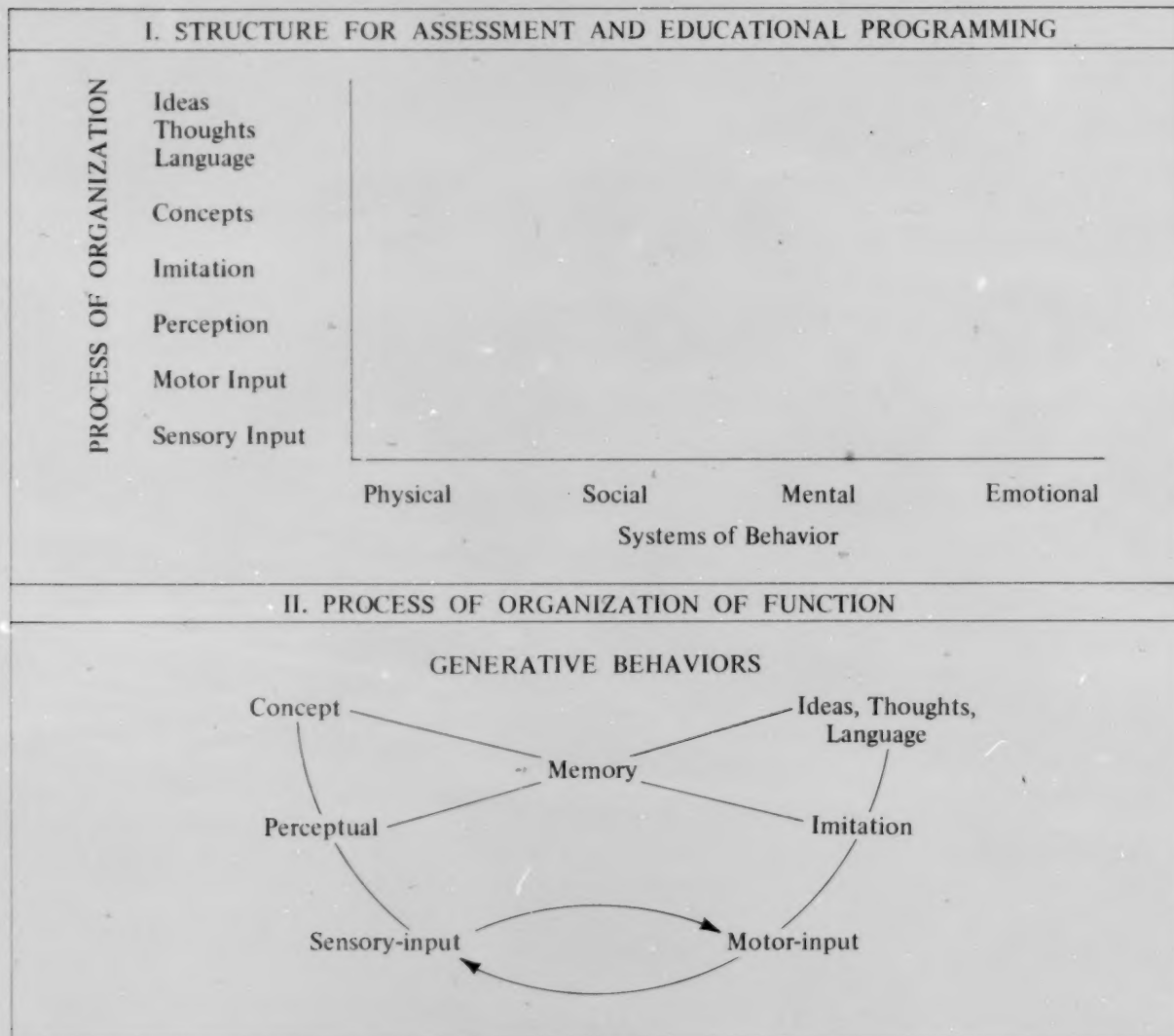


Fig. 3. Process teaching: a system approach (Hammer, 1974)

coordinator of the report information and presumably could act to attain more interrelated thinking on the part of individual specialists.

In 1962, Joan Shields of Condoover Hall commented:

Our general feeling is that while every use should be made of tests, machines, experts, whenever and wherever available, the factors of human intelligent observation and care by people working with the children are equally important. Nobody should refuse to carry out the assessment and eventual education of deaf-blind children just because expensive equipment and experts are not available. Just get on with the job. In time equipment

will become available and you yourselves will become the experts.

Preliminary Data

Myklebust (1956) described a generally valid approach to collection of preassessment materials on the child. Donlon (1970), in describing the Syracuse University psycho-educational evaluation procedures, stated that prior to the evaluation, developmental information was collected and school and anecdotal records and all historical data, such as previous medical tests and treatment data, were obtained. Two rather complete forms

for collecting historical data are available: the *Mountain-Plains Regions Developmental Scales* (undated) and the *Michigan Manual for Assessment of a "Deaf-Blind" Multiple Handicapped Child* (1973).

Assessment Sites

Some educational assessments that are carried out by teams of specialists under a medical structure require the student to travel to a major center and then to be seen in different rooms by different specialists (Conlon, 1971). Hitzing (1974) explored the possibility of a traveling interdisciplinary regional team that would work with a "home team." The regional team would assess a child while the home team observed. Each would consider its own report, and then discussion would ensue. The project was designed as a training project for local assessment teams and as a means of communicating assessment information within the region. Moriarty and others (1971) recommended observation of the child in a variety of situations: with his or her parents or surrogate parent, in the classroom, outdoors, and in situations with and without a familiar adult. Robbins, (1975) describes the benefits to families of general educational assessment procedures conducted in a school that offers service to a large population of deaf-blind students of all ages and a wide range of developmental and academic levels.

Techniques for Collecting Primary Assessment Data

According to Donlon (1961), two general techniques are used to collect data on the child:

Standardized or objective descriptions. Donlon points out the need for more objective, scientific, and valid research methods for (1) reporting performance on standardized test measures, which already have built-in procedures and scoring criteria; or (2) clearly describing situations or behaviors of importance so that another person could name the same behavior if he or she saw it again.

Subjective descriptions. Subjective descriptions, on the other hand, offer different data. According to Donlon, there is "much to be said for emotional attitudes and the factor called clinical insight when dealing with human relationships." However, he embarked on a study that also points out the misunderstandings resulting from using objective descriptions too freely.

In the early days of education for the deaf-blind, no standardized or objective procedures were available for describing behavior or learning of

children. However, teachers still noticed differences among students and made records of some of the differences in their choice of descriptions in the reports or correspondence about the student's behavior, personality, and progress. For example, the following phrases, representing the thoughts of a number of people, were pulled from the records on Leonard Dowdy, a very capable deaf-blind student who made ready progress in language, academics, and life: "so anxious to learn . . .," "so normal in every way . . .," "eager and active . . .," "a bright and interesting little fellow . . .," "willful ways . . .," "had to have a reason for everything . . .," and "inner motivation to explore" (Stenquist, 1974).

Curtis and Donlon (1969) reviewed the records of 70 multihandicapped children who were evaluated by means of a team approach that was heavy on subjective description and light on objective data. They found 1,646 different terms used to describe the children, with a very high percent referring to judgments, observations of behavior, and physical status rather than to formal test results or functional skills. The reports, according to Donlon (1969), all included "inconsistencies, repetition, and incompleteness." The percent of practical recommendations was very low. Curtis and Donlon recognized the need for more standardized procedures for communicating information about the child from person to person or from one agency to another. They proposed a videotape protocol, with generally standardized procedures for objectifying the adult's impressions of a child. Elzey (undated) designed an *Experimental Observation Rating Instrument* to "facilitate systematic recording of the behaviors of a preschool child," and to "facilitate obtaining objective descriptions of individual children and their interaction with their school environment." Elzey listed a set of variables: type of experience, child's involvement level, other direction, person involved, activity level, mobility, self-direction, cognitive behavior, expressive communication, and effect. A list of categories was included for each. A category was to be checked for each variable at one-minute intervals over a 15-minute period. For example, categories for "type of experience" were "none," "sensory," "manipulative," "large muscle," "social cognitive," and "other"; and for "involvement level," "none," "low," "medium," and "high."

Structured Versus Unstructured Environments

Most agencies recognize the importance of assessing the child in two kinds of situations: (1) a

structured environment in which definite tasks are offered to him or her and in which there is implied necessity for personal interaction with the adult since the adult is making requests, giving directions, offering praise or correction, and communicating; and (2) unstructured environments in which the child is left free "to do" with whatever is available whenever he or she wishes. This framework, used by Myklebust (1956), has always been a basic structure in the Perkins assessment scheme (Davis, and others, 1962; Robbins and Stenquist, 1967). The unstructured play environment in the Robbins and Stenquist scheme includes a wide variety of toys and at least one adult in the room. Other unstructured situations would be those occurring at dinner time, on the playground, and at bedtime. The videotape telediagnostic protocol of Curtis and Donlon (1972) is designed with fewer materials to suggest to the child the possibility of personal interaction with the adult present in the unstructured situation. Browning (1974) recommends an adaptation of the models for structured and unstructured situations used in the telediagnostic protocol.

Approaches to Cognitive Assessment

Burroughs (1970) summarized several approaches to solving the problem of assessment and adopted the following terminology:

1. Perkins approach (normative data)—This approach is characterized by persistent use of standardized tests in one's own population so that norms for that situation are gradually developed.
2. Jamieson approach (practical adaptations)—In this approach items are chosen from developmental tests (the *Cattell Infant Scale* and *Denver Developmental Scales*); materials are adapted; and observations of problem-solving and ways of learning are then made.
3. Hammer approach (specific protocols)—Areas believed to be important for curriculum are selected, and developmental scales are elaborated in each (Hammer, 1974; Ficociello, and others, 1974).
4. Guldager approach (Piagetian scales)—A scale concerning body image imitation and body concept based on Piaget's six stages of development in the sensorimotor period was developed. Observations result in assigning the child to a particular state and then drawing upon the outlined developmental tasks that are appropriate. Assessment is directly applied for educational purposes.

5. Elzey approach (experimental scales)—Two new scales for the purpose of objectifying observations were designed. One scale includes items that represent "critical behaviors in the child's functioning" in behavioral terms and includes statements of relative competence in performance. The other scale is the *Observational Rating Scale*, which was described previously.

What Are the Time Requirements?

Time requirements for a general educational assessment differ somewhat, partly on the basis of the agency position regarding the psychology of the deaf-blind. For example, Lyall (1972) and Henry (1973) have developed a ten-minute screening test to be used to assign retardates in state schools to one of several program levels and to assign a rating usable for making priority decisions for placement in programs. A total, multidisciplinary evaluation at Syracuse (Curtis, and others, 1970) requires four and a half days; the evaluation at Peabody requires five days. However, some suggest that this time is too short because of the complexity of the children. Brandt (1969) recommends three or more months because of the "need for in-depth evaluation due to the fact that children are far below their chronological age." The Michigan School for the Blind (Monk, 1973) has a diagnostic classroom approach (five to six weeks) with a four-day clinical study at the Institute of Study of Mental Retardation and Related Disabilities.

The Perkins School for the Blind has offered varying time schemes. Early in its assessment undertaking, children were given diagnostic trial periods of a year or more in the department to determine if language instruction readiness was latent. Later this trial period was dropped. During the past rubella epidemic period, evaluations lasted four and a half days, with three or four families attending at the same time. The advantages of having the interaction of families and having evaluations in a school with a rather wide cross section of the deaf-blind population are that this population lends a background of experience to the staff and permits parent observation of other children to gain perspective on problems of their own child.

The time requirements for measurement of student progress are equally variable, ranging from a statistical technique carried out on a set of ratings obtained with a single three-year period interval (Tweedie, 1974) to teacher measurement of progress using developmental checklists four

times each school year. Apparently, no reference is made in the literature to any definite plan for team reassessments of individual students to ensure appropriate program placement. The nature of the deaf-blind population would suggest changing needs as a prime characteristic, with movement into or out of classes focusing on sensorimotor development into classes focusing on language instruction, shifting hearing level, and changing visual status. Absence of comment on this in the literature is an omission of concern with regard to organization of general assessment procedures.

Purposes of Educational Assessments

Burroughs (1970) points out that in choosing assessment instruments or approaches, one needs to ask, Who needs to know what? She points out that the three categories of purpose require different techniques and even different reporting: (1) legal purposes such as qualifying for particular programs or financial aid, which might require labels or numerical scores; (2) medical purposes such as test data relating to fitting of hearing aids or glasses or developmental levels to assess need for special therapies; (3) educational purposes to choose program, to select methods, to identify his or her place with reference to a vague curriculum of life, to choose mode of communications, to identify learning problems, to select remedial techniques, and so on.

The literature does not always state clearly the relationship intended between approaches, tools, or techniques and assessment purposes. Therefore, another category should be added to those above: planning purposes for data that will enable families to plan for their futures financially; to make geographical choices, if necessary, professionally; and to enable schools, local programs, regions, and national administrative staff to plan for future program needs.

No one national plan has been developed for conducting educational assessments of deaf-blind children. Competency of staff doing the assessing, physical location or professional association of assessment groups, preliminary data collected, techniques for collecting primary data, choice of approaches to cognitive assessment, and length of time required all vary, depending on the purpose of the assessment.

Tools and Techniques for Educational Assessment

No norms, no standardized tests of intelligence, and no means of assessing cognitive behavior are

available for use with the deaf-blind. However, since 1956, when Helmer Myklebust initiated the research and testing program at Perkins, tests standardized on blind, deaf, and normal groups have been used with partially seeing deaf-blind children. A body of knowledge does exist with regard to the performance of partially seeing, deaf, or hearing impaired children on standardized tests. However, it is scattered and difficult to pull together due to the variability in tests used, in clinician approaches, and in complexity of variables among the population itself.

According to recent responses to a questionnaire sent to all regional centers and a few major evaluation centers and from evidence throughout the reference literature, many agencies continue to use normative tests and feel comfortable with them for purposes of describing on a rating scale gross differences in functioning by comparison with the scores of the normative population of the test itself (Robbins and Stenquist, 1967; Cochran, 1969; Chess, 1971; Moriarty, 1971; DuBois, 1975; Das, 1975).

A list of standardized tests and a small number of new nonstandardized tests in use among agencies routinely assessing deaf-blind children are presented on page 139.

Reported Results on Use of Tests

During the period of initial use of standardized tests at Perkins, Stenquist (1959) points out the need to recognize the individual effect of sensory and cognitive handicaps on quantitative test scores and the consequent need to consider simultaneously qualitative behaviors in use of vision, use of hearing, use of any or all senses for exploration, ongoing communication, response to people, response to objects and toys, level of learned everyday behaviors in self-care skills, level of curiosity, quality of attention, learning improvement with repeated trials, emotional behavior, personality traits, and degree of involvement in approach to problem-solving on the presented tasks. Since Stenquist (1959), attempts have been made to objectify behavioral observations in many of these areas (Elzey, 1974; Curtis and Donlon, undated).

Robbins and Stenquist (1967) offered descriptive information on some characteristics of 88 congenital rubella students who had been or were enrolled in the Department for Deaf-Blind Children at Perkins. They included (1) a listing of standardized intelligence tests and developmental tests on the sighted, hearing, deaf, and blind populations

and a selection of supplementary test items covering a mental age range from birth to adulthood, sampling cognitive abilities as well as personal-social skills; (2) supplementary, innovative material on assessment of a parallel cognitive-related skill (for example, communication and language of the nonverbal, nonoral type); and (3) brief summary statements on visual and auditory acuity, etiology, and educational opportunity.

The authors speculated on the probabilities for communication development and educational growth of identified profile types in the total group, basing speculation on the children's behavior over the years and on background knowledge of deaf, mentally retarded, blind, and cerebral palsied children and their progress. The points to be made were that important educational differences existed in the group, and the differences had implications for program needs.

The *Ontario School Ability Examination* for deaf children was among those tests used in the study of congenital rubella children. The authors judged the test as sensitive to some differences among the partially-seeing, congenital rubella group since the spread of scores ranged from 11 through 95:

<i>Ontario IQ</i>					
scores:	30	30-49	50-69	70-89	90-100
Number of students	6	6	2	3	9

All reports on a large group of congenital rubella children (Robbins and Stenquist, 1967; Cochran, 1969; Chess, 1971) showed a wide range of test scores, seemingly suggesting differences among the population in demonstrated cognitive capability at the time of testing.

Since the writers were worried by the confusion often occurring as to whether item or test failures were due to limited vision or immature thinking, a somewhat naive but not totally uninformative attempt was made to correlate visual capability with test scores. The suggestion was that vision was not an adverse factor, witnessed by the incidence of high scores among children with very impaired vision. However, without actual evidence, the correlation of a distance vision test with a performance test requiring near vision leaves the results open to skepticism. Perusal of the tests listed on page 139 shows a large preponderance of very visual tests using very small picture items (*Leiter International Performance Scale*, *Hiskey-Nebraska Test of Learning Aptitude for the Deaf*, *Wechsler*

Intelligence Scale for Children (WISC), *Goodenough-Harris Draw-a-Man*, and so on). Assuming that most clinicians use reasonable judgment, this array of tests would seem to imply a great deal of functional vision in the deaf-blind population.

Robbins and Stenquist (1967) suggested that the *Ontario School Ability Examination*, supplemented by other described behavioral observations of play and communication and several additional performance items at or below a two-year mental level (Wallin pegboard, Gesell formboard), is a useful test instrument for screening children for general program type and level needed and particularly for readiness for school, since children could be compared on a ranking system. The *Ontario School Ability Examination* items and communication requirements were seen as very appropriate sampling behaviors needed for participation in a school setting. School was implicitly defined as a situation in which an exchange of attention, communication, and information occurs between teacher and student; in which the student has developed beyond the sensorimotor period and is able to consider ideas by imagery and to approach problems thoughtfully rather than manipulatively; and in which imitative behavior is needed to learn beginning language. Given this conception of school, Robbins and Stenquist developed guidelines for classifications of educability based on several factors seen as suggestive of minimal educability: *Ontario School Ability Examination* score of 50 or above at age six years or older; evidence of emergent representational thinking in play; evidence of emergent ability to refer to things outside of and separate from oneself in communication with another person.

Stenquist also comments on two other tests that include primarily symbolic or representational test items: the *WISC*, standardized on normal children and used extensively with deaf children; and the *Hiskey-Nebraska Test of Learning Aptitude for the Deaf*, standardized on deaf children. Since the *Ontario School Ability Examination* includes no representational items, the four subtests using pictures from the *Hiskey-Nebraska Test of Learning Aptitude* were suggested as additions to the *Ontario School Ability Examination*. Also pointed out was their diagnostic value in identifying the child with high nonverbal, perceptual-motor, manipulative, and pattern-making skills but low in the representational capability that is more closely correlated with language-learning behavior. The *Hiskey-Nebraska Test of Learning Aptitude for the*

Deaf pictures are small, and Stenquist suggested that children with less than 5/200 corrected distance acuity not be given the test and that the visual capacity of the child as demonstrated on other, simpler, identical in size, picture-matching material or on the simplest *Hiskey-Nebraska Test of Learning Aptitude for the Deaf* picture item could be used to differentiate visual versus cognitive failure.

In discussing the *WISC*, Stenquist commented that the occasions when it could be administered were few because of its high symbolic content and the great degree of difficulty that the partially-hearing deaf have with symbols. Elioseff (1971) cautioned against the tendency to avoid offering test items that one knows a child cannot perform. This caution is an important one. If a range of items sampling different areas of thinking or performance and different types of mental abilities is not offered, when one describes what the child can and cannot do, one will certainly not differentiate among the learning problems of individual children. The developmental scales for the most part sample behaviors that can be learned: perceptual-motor or perceptual-cognitive behaviors. The standardized intelligence test described here samples cognitive functioning applied to a variety of task situations.

A wide range of performance and a variety of differences have been described in the congenital rubella population by Chess (1971) and Cochran (1969). The Cochran study used the *Denver Developmental Screening Test* and the *Gesell Developmental Tests* with the congenital rubella group enrolled in Baylor's Diagnostic Nursery program. Cochran (1969) commented:

Immature or maladaptive behavior, inappropriate emotional responses, and lack of environmental awareness have prevented optimal group participation. This combination of factors prevents performance on standardized age-appropriate tests of intellectual functioning from being comparable to that of the normal child. Thus all of the children measured in the range of decreased intelligence function regardless of potential intellectual ability.

Chess (1971) used the *Cattell Test for Infants and Young Children* and the *Stanford-Binet Intelligence Scale, Form L-M*, supplemented by a general personal-social skill listing, observations of temperament, and parent interviews, in the new York University study of 243 preschool congenital rubella youngsters. The battery discriminated among the children, and Chess made the following generalizations:

1. The study revealed a definite correlation between the number of physical defects and the display of behavioral pathology, although there was not "a necessary or inevitable relationship."
2. Congenital rubella is not only a multisystem disease, but it is also a continuing disease. Changes and additional handicaps should be anticipated as the child grows.
3. Mental retardation is one of the major consequences of congenital rubella; 37 percent of the group had various degrees of mental retardation, most falling in the severe to profound category.
4. Central nervous system damage is highly probable in children in the group and may be responsible for distortion in thought processes, delays in cognitive advances, and difficulties in hearing or in use of hearing.
5. The incidence of autistic characteristics was high; 18 children were identified as being autistic.
6. A discrepancy was common between routine daily performance and a child's maximum performance. Chess stated that it is vital to report both so that parents and teachers can realistically judge what demands and expectations are appropriate.

Critique of Normative Tests for the Deaf-Blind Population

As was mentioned earlier, psychologists and educators in general are skeptical about the use of normative tests. The intent of a normative test is to enable one to compare an individual's score with those of an identified group or to compare one group with another group. Rick (1971) points out that "a percentile or a stanine or a mental age or IQ has no meaning apart from the observed collection of people's scores (norms) on which it is based" and that the nature of the normative group will determine the "look" of the individual's score. Persistent problems occur in selection and in interpretation when one applies tests standardized on other groups, and for this reason many people are most cautious in using such tests.

Rick and many persons assessing deaf-blind children feel that local norms that are developed by using a test on a group are useful when looking at what a group or an individual within a group can do but are not as useful for looking ahead to predict what an individual may be expected to do in the future.

In the deaf-blind field, critique of use of standardized tests has come primarily from persons working with the more severely impaired deaf-blind children because these children almost invariably score at the minimal level on the scale. Stillman's objections include the following: (1) time limits are often adverse to the child's best performance; (2) tests are based on the assumption that communication with the child through auditory or visual channels is possible; (3) tests are based on the assumption that the child has sufficient language base to comprehend elementary instructions; (4) tests are based on the assumption that the child has developed socially to the extent of being able to interact with an examiner, who is usually a stranger; (5) frequently included are items that require experience and knowledge of the environment that a deaf-blind child lacks because of his or her sensory impairments and general delay in language and social development; (6) components when usable are not easily translated into more effective educational or therapeutic programs; (7) these tests must be administered by a specialist; and (8) modification of items throws the norms off.

The effect of such critiques led to expansion of developmental scales focusing on self-help skills, motor behaviors, and communication/language behaviors, which has proved helpful in basic assessment of children performing below a three-year mental level and which has led to a curriculum approach for the early level of sensorimotor development. However, several comments should be made in response to some of the objections. First, it is true that time limits often add a factor adverse to determining a cerebral palsied or visually impaired child's best functioning; but it is quite possible to select tests that are not timed (for example, the *Ontario School Ability Examination*, the *Leiter International Performance Scale*, the *Hiskey-Nebraska Test of Learning Aptitude for the Deaf*). Second, for the most part in the deaf-blind population, residual vision or hearing is available for communication purposes. Third, tests standardized for deaf children are based on the assumption that communication can be accomplished through situation and simple gesture only. Fourth, tests differ in the degree of social interaction necessary; for example, the *Ontario School Ability Examination* requires a great deal of social interaction, while the *Leiter International Performance Scale* requires very little. Social interaction (attention to persons, imitation, a search for communicated intent) is vital to language and is therefore of

interest in the test situation. Fifth, components are not translated as readily into a daily therapeutic program as a system of sampling knowledge within the context of a curriculum; however, a competent school psychologist can, with such standardized tests, make recommendations as to the level of instruction that is needed in particular areas and recommendations as to the most desirable instructional methods. Sixth, some test items do require a background of experience (the *WISC* picture story arrangement subtest, for example) that a deaf-blind child might not have. However, many tests require no background of experience, but do require the ability to assess the presented, visual situation and the ability to find a solution. Some children can assess visual-perceptual material and can build visual configurations at a high level but are totally unable to find more subtle relationships among simple pictures or to reproduce a patterned movement occurring in a time period. Such differences are associated with particular classroom and life-long learning problems. Seventh, special tests need to be given by specialists who have a broad base of testing experience and who can relate the information to other disabilities, to general learning strategies, to program needs for the total group, and so on. This complements the need Stillman emphasizes for more detailed descriptions of early behavior. Teachers could use such descriptions to make assessments and could apply the descriptions directly to the curriculum. Eighth, the experienced clinician does not report or consider only end performance. Rather, he or she makes a wide range of behavioral observations on learning, problem-solving, communication, motivation, and effect by using the standardized tasks as an objectifier for his or her own observations of and generalizations about each child. Hence, to an experienced clinician, any reputable test can serve as a springboard for crucial observations related to child management.

Summary

To include selected standardized intelligence tests in an assessment battery seems desirable. To choose to use nationally one or two of the tests that have been used most often with the deaf-blind population is also desirable so as to utilize the accumulated information for longitudinal study of change and to build a body of information on the deaf-blind. An organized system for analyzing subtest results, problem-solving strategies, and affective and communicative behaviors encountered in the standardized test situation could be

developed and geared toward practical educational issues. Examination of visual acuity or of capability with respect to ability to visually appreciate subtest items is vital, and adaptations of test items that are deemed necessary should be described so that they can be replicated from one test situation to the next.

Standardized or normative intelligence tests have been used with partially-seeing (as low as 5/200 distance acuity) deaf or hard-of-hearing children for particular purposes: (1) for screening children for general program need, since general cognitive level is describable by considering subtest performances and basal and ceiling level on a particular chosen test; (2) for efficiently describing subgroups of children with particular profiles, including subtest scatters affecting choice of educational procedures or situations; (3) for planning regionally or nationally; (4) for effecting a standardized situation in which to sample the child's ability to think, to consider, and to receive nonverbal directions; and (5) by using total scores as one reasonably objective measure, for ranking groups of children, if necessary, for purposes of making program cuts or shifts of population among programs.

The appropriateness and usefulness of the information gathered from the test will always be dependent upon the clinician's ability to select a test for the individual, to rate peripheral behaviors, to utilize adjunct measures, and to interpret results into practical terms relating to classroom or everyday behavior.

Use of Developmental Schedules

The use of compilations of developmental checklists has received impetus from (1) dissatisfaction with standardized tests for describing the more severely impaired children; (2) the fact that these tests have been used for years by physical therapists and occupational therapists in working with severely impaired children and were readily applied to the deaf-blind population (Fieber, 1972; Tanabe, 1972); (3) the fact that they relate directly to, and in fact define, areas of intervention and curriculum for young children; and (4) the fact that they can be used by teachers, without the aid of specialists, for assessment, goal setting, and measurement of progress. The latter is particularly important for teachers in isolated classes without supervisory support. Fieber and Tanabe outlined the importance of developmental assessment for defining the problems of the child, defining the level of the child, setting goals, and measuring progress. They also pointed out the importance of

developmental assessment as a potential common instrument in the test batteries that are used in various situations and for various testing needs. Their scales are based on the *Denver Developmental Screening Test*, *Bayley Scales of Infant Development*, and *Gesell Developmental Tests*. A copy of the checklist is included in the Omaha Workshop proceedings (Horsley and Smith, 1972). Their score form is set up by age levels rather than by areas, scores of plus or minus are given, and quality of performance and degree of assistance needed is judged by the following scale:

1. Is unable to perform activities
2. Accomplishes activity with more than usual assistance
3. Accomplishes activity independently but in more than average time or in an awkward manner
4. Accomplishes within normal limits and normal time; compatible with normal
5. Has reached maximum due to disability

Other scales include similar qualitative performance ratings. Performance quality in scoring as a factor of persistence (+/- if he or she can do it, but doesn't always) in a mentally retarded population is recognized in the *Vineland Social Maturity Scale*. Fernandez (1969) noted the same behavior frequently in her congenital rubella population and chose to score positively a "can occasionally" even if he or she "doesn't always." The "can occasionally" is viewed by Fernandez as an indicator of future potential.

A variety of developmental scales has been compiled through the regional centers throughout the country. Primary sources seem to be the Gesell, Maxfield-Field, Bayley, and Vineland instruments, although sources of items are not always mentioned. A listing of all the different sources utilized would probably total 40 or more. Areas of development sampled vary from scale to scale as does the number of items in each area. A summary of the areas of observation and an indication of the number of items for each of the areas for three of the most comprehensive, published, or readily available scales designed for the deaf-blind and for the several scales designed at Peabody and DuBose and Associates is presented on pages 141 and 142. This summary is offered to (1) point out areas of concern in assessing the child, possible strengths in each scale, and probably overlap from scale to scale; and (2) suggest that a compilation of scales by a committee might be a reasonable step for consideration.

Callier-Azusa Scale

The *Callier-Azusa Scale* is a scale of normal development, extending most completely from birth to age five years, with additional items in some areas to age nine years. It was designed to be used by teachers for the following purposes:

1. To assess the developmental level of children for whom other methods of assessment are inadequate because of the requirement for language abilities, cooperation, or intact sensory modalities; or because they lack comprehensiveness at lower levels
2. To measure progress over a period of time to determine the overall effectiveness of programming or the effectiveness of a specific educational or therapeutic technique for an individual child
3. To provide guidance but not a teaching program for planning developmentally appropriate programs for individual children (Stillman [The *Callier-Azusa Scale*, 1974] cautions against using such a scale to teach or instill isolated behaviors in a school setting that is unrelated to real life situations.)

A test-profile (a visual graph of item performance) is used for recording performance and comparing areas. No known information regarding interpretation of test profile for purposes of program planning is available nor has any comment been made on effects of sensory capacity. In this scale more emphasis is placed on the sensorimotor end of the developmental continuum than on the more strictly cognitive areas. Items are not written in behavioral objective form; however, examples of those behaviors that are referred to are given to clarify meaning: (a) feeds self with spoon, and eats finger food independently; (b) identifies or obtains, when asked, three familiar objects that are in his or her immediate surroundings and that he or she uses in the course of the daily routine (Example: cup before snack, towel before bath, coat before going outside, ball before playing, and so forth); and (c) has concept of size (Example: When shown a big ball and a little ball and asked to "show me the big ball," child points to correct one.)

Items are scored only on the basis of pass or fail, but the criteria for determining pass or fail are not entirely clear. However, Stillman has recognized the problem of variability in scoring from person to person.

Michigan Scale

The *Michigan Scale* was compiled for use by teachers in setting goals for individual young deaf-blind, multihandicapped children and, as an educational guide, for use by supervisors in training house-parents and paraprofessionals. Normative reference levels for items are not given. Scoring is by plus or minus only. Items are written in relatively clear sentences, but not in behavioral terms: (a) uses spoon with some spilling, no rotating; (b) tolerates and dislikes adult attention and contact; and (c) child has concept of pictorial body parts corresponding to his or her own body.

While emphasis is on the earlier levels of development, items could not be arranged to compare levels across the subscales, undoubtedly because many small skills or informational areas are included without reference to a stage of mental function or strategy. The record form is therefore cumbersome for reporting, being descriptive in nature with a reference to current skill level, short-range goal, and program statement. The guide contains a list of terms relating to the eye, but it includes none relating to auditory testing nor to any other area of assessment. A noteworthy attempt is made to sample certain facets of higher level communication skills in areas of cognitive development as well as affective, motivational correlates. Comparison of the *Callier-Azusa Scale* and the *Michigan Scale* suggests that the two may be useful to teachers of the deaf-blind, particularly those up to about age four, for focusing more strongly on noncognitive behaviors. A separate developmental, diagnostic-curriculum written in behavioral terms to encompass in detail all levels of cognitive development with respect to information to be processed is needed.

Mountain-Plains Scale

The *Mountain-Plains Scale* is designed for use by teachers to "obtain base-line data for appropriate use . . . in the classroom" and to measure progress at suggested nine-week intervals. The scale data are meant to be used for development of behavioral objectives for an individual child. The format is somewhat unsettled; some items have sublistings that refer to degree of accomplishment. No information on interpretation is provided.

Peabody Scales

The *Peabody Developmental Motor Scales* (Folio and DuBose, 1974) and the *Inner Language Scale* (Branstetter and DuBose, 1974) are used in some regions. The motor scale includes 130 fine-

motor items and 168 gross-motor items. It was designed to be used to assess children between birth and seven years of age and to outline skills that have been mastered, those that are being developed, and those that have not yet been included in the repertoire. Five categories, from "total dependence" to "complete independence," are utilized. The manual includes corresponding activities for skill building so that direct application to daily education is possible.

Other Scales

A variety of other scales is available, among which the following are of particular interest:

1. Koontz (1972). This is a very extensive scale (395 items) for use in assessing profoundly retarded children. Sources (18) are given. Tasks are divided into year levels up to four years and are written in behavioral terms. A grid-record is offered to permit quick visual perusal and record-keeping. Areas sampled are the following: gross motor, 97 items; personal-social, 90 items; fine motor, including imitation, 103 items; and language, 149 items. The format of items, extensiveness, and record-keeping system deserves attention.
2. Groves (1971). Groves offers the following scales: general motor development scale, 66 items; general personal-social scale, 58 items; general oral language scale, 50 items; vocalization and speech scale, 18 items; receptive language scale, 56 items; and cognitive (adaptive) scale, 42 items.
3. Baldwin and others (1974). The Northwest Region is in the process of compiling and developing comprehensive evaluation instruments. Apparently, a curriculum (*Teaching Research*, 1974) is being used with a checklist of 231 items, sampling 174 specific skills, to determine the gains of students in the region.
4. Robbins, Elioseff, and Banta (Horsley and Smith, 1972). Two developmental lists (*Non-Verbal Communication* and *Personal-Social Behavior, 0-2 Years*) were developed at Perkins School for the Blind. The scales encompass a wide range of behaviors—sensory, affective, social, communicative, sensorimotor, and cognitive. Separate scales were developed for the totally blind, deaf-blind, and the partially seeing deaf-blind.
5. Anderson (1973). Kathryn Anderson developed observation forms of visual, auditory, personal-social, and physical behaviors and

more detailed developmental checklists in language, perceptual development, and conceptual development. They were intended for use by teachers and ward staff to evaluate children, assist physicians and psychologists who work with the children, explain to parents the child's strengths and weaknesses, and help the teacher in planning individualized classroom and home-teaching activities.

Summary

A wealth of material drawn from standard sources on development and applied to deaf-blind children is available. Duplication of effort is evident from region to region, and areas of strengths differ from one scale to another scale. There would seem to be merit in combining efforts to produce (1) an outline of areas to be assessed; (2) summary checklists for each area; and (3) a guide for interpretation of profiles.

The tendency to combine developmental scales to develop more extensive item listing per se was the first step toward curriculum development for young deaf-blind children. An attempt to build developmental assessment procedures and outlines of development into curriculum for more than the traditional early childhood areas of development is a definite need now that the congenital rubella population is growing older, is learning language, and needs to consider ideas and information. Development of broader curriculum will enable those involved in assessment of the deaf-blind to comment on and describe more clearly by means of criterion-referenced testing what a child can do.

Communication and Language Assessment

A number of areas will be considered in the discussion of communication and language assessment.

Proto-Symbolic Behavior and Cognitive Development

Robbins and Stenquist (1967) devised two scales to be used in making observations of partially seeing deaf or hearing-impaired children in their play with objects and in their spontaneous nonverbal communication with people. The scales were developed as a result of several influences, including Heinz Werner, Jan van Dijk, and Helmer Myklebust. Observation over the years has suggested the validity of several assumptions. As a base, in consideration of behavioral profiles, the assumption has been made, and descriptively supported by Robbins (first 1969 reference, 1971, first 1972 reference) and Elioseff (1971), that

language growth (nonverbal and verbal) and language capacity are linked to, but not always in perfect, predictable correlation with, cognitive development nor with gross-motor milestone achievements. The following general observations are offered:

1. A cognitive level, measured on visual performance tests of only the past three years, is necessary before a partially seeing, deaf child can begin to engage in actual language learning.
2. In the presence of deafness and some visual impairment, prognosis for language learning is related to test performance scores indicating rate of development and the presence or absence of proto-symbolic behaviors (emergent signs of representational behavior and ability to cope with cognitive tasks requiring the perception of relationships, not of visual patterns or shapes).
3. There is in this population a generally predictable correlation between degree of retardation; demonstration of representational behaviors and effect; and eventual language structure, vocabulary, and nature of ideas conveyed.
4. Prognostically and for ongoing education, one must differentiate between signal and symbolic communicative behavior in children with language disorders.

Innovative Tests of Nonverbal Communication

The importance of assessment of communication itself led to the development of several innovative tests, which are described in some detail in various published and unpublished sources:

1. *Test of Causality* (Robbins, 1971). This is a Piagetian-derived scale that is based on assessment during the subperiods of the sensorimotor stage. The child's method of "requesting" repetition of the action of a mechanical toy is rated.
2. *Meaning of Objects* (Robbins, 1971). A set of toys is presented for the child's rejection, handling, inspection, manipulation, experimentation, or comment. Toys appropriate for "releasing" behaviors from the four-month to the twenty-four-month level (re: normal development) are included. Assessment is based on Piaget subperiods:

Four to eight months—Action with objects: mouthing, looking, holding, shaking, bang-

ing, dropping, pulling apart, repeating an action

Eight to twelve months—Examination of objects: takes apart, notices details, seeks help to make things happen

Twelve to eighteen months—Experiments: throws, fills, stacks, arranges, compares

Eighteen to twenty-four months—Emergence of imagery with a knowledge of space world and object function: imitates, engages in social play and representational play, "considers," and "reflects"

3. *Test of Arbitrary Sign Learning* (Piagetian-derived in part). An evaluation is made of the child's response to an arbitrary hand movement (nonrepresentative of form or action of the referent) made by a communicating adult and associated with a situation culminating in a primitive reinforcer (movement, visual sensation, or food) that is at first readily available; secondly, contingent upon a particular sequence of behavior; and finally, contingent upon the use of the sign by the child to request the absent reinforcer. Separate rating scales are described for visual presentation of the sign and for motor-programming of the sign by manipulation of the child's hands, since it was found that children who could not reproduce a seen movement could sometimes appropriately reproduce a movement that had actually been performed by manipulation of their hands (Robbins, 1971).

4. *Signs for Everyday Objects* (unpublished description). A set of everyday objects (comb, cup, spoon, hat, and sunglasses) are requested, one by one, from the student by descriptive sign-gesture and named in the same manner by the student on "request" (by demonstration).

The Robbins tests were originally developed to be used with preverbal or nonverbal, hearing impaired or deaf children to: (1) sample behaviors believed to be closely related to language and its use; (2) permit participation by the totally blind-deaf child as well as the partially seeing; (3) involve high motivation to encompass early levels of cognitive behaviors and absence of social motivation or intrinsic curiosity and "will to do" on the part of the child; (4) use materials and procedures that could be standardized; (5) permit participation and rating of the behavior at any level of development; (6) assess behaviors important to habilitation; (7) permit learning during the session

to offset experiential differences from child to child; and (8) focus on description of organizational patterns used by the child, not just a plus or minus score.

These Perkins scales evolved out of a hierarchy of levels of behavior seen in communication, originally derived from Myklebust and expanded from a variety of influences into the framework offered in Figure 2.

Related to this general area of assessment is the Piagetian-derived scale of Guldager (1970), which is a body image scale for the purpose of providing "a framework for clinical judgments about the child's developing body image as manifested by imitative ability and possession of object concept." Guldager was influenced by van Dijk, who theorizes that movement is the basis of communication development and development of a sense of body as entity. Activities are suggested in conjunction with each subperiod to promote development. Branston and DuBose (1974), using a number of sources, including Gesell, V. Guldager, Robbins, Uzgis, and Hunt, have organized an *Inner Language Scale*, which consists of 20 items, five under each of the following categories: object concept, object permanence, causality, and imitation. One item is provided each of five age levels running from one to four months to eighteen to twenty-four months. None of these tests has actually been standardized in procedure, scoring, or interpretation, and none has been evaluated objectively as to validity.

General Language Level

A wide range of oral language scales are available throughout the literature listed at the conclusion of this paper, including those already mentioned in the discussion of developmental scores. Usually, simply by a change of mode, these oral scales are used also with students who use fingerspelling. Elioseff (1971), in a statistical study of a group of older Perkins students, suggests that the *Peabody Picture Vocabulary Test* is satisfactory to use for measurement of progress (as are the *Stanford Achievement Tests* and the verbal tests of the *Wechsler Intelligence Scale for Children*). Tests reportedly used in various regions to assess the language of deaf-blind children are reported on page 139.

Tests to Determine Input Mode

Input may be given verbally or manually.

Tadoma method. No one has actually considered how to determine whether a deaf-blind child

should or should not use the Tadoma method. Robbins (1967), in brief reference to a case study, referred to seemingly improved speech reception when the Tadoma technique was used for speech reception by a partially seeing, hard-of-hearing rubella child. Teacher observational support of the benefits of tactual speech-reading to another partially seeing, hearing-impaired child was given by Van Arnam (1971), who found that it focused the student's attention and was an aid to both discrimination and speech improvement. Record's (1971) test results with three students at Perkins suggested that profoundly deaf students with vision of 20/200 or less would profit in speech-reading accuracy from tactual speechreading in addition to visual input. Van Dijk suggested that the technique was useful with educable deaf-blind students until they reach the level of academic learning and that it is then that "fairly slow, nonhygienic and emotional problems arise" and should be replaced by fingerspelling.

Manual versus oral. Robbins (first 1971 reference) summarized factors that could be used in objectifying the decision regarding whether a student should pursue speech development or utilize a method of manual communication (specifically, fingerspelling). Further practical discussion on this point is offered by Van Arnam (1970).

Summary

McCay Vernon (1969) commented: "Aphasoid involvements are almost invisible in deaf children, despite their extreme importance." A study of 1,468 deaf students from the California School for the deaf, Riverside, was made using a teacher questionnaire to identify the students who had "marked difficulty with language greater than that expected owing to deafness or level of intelligence." The results showed that language-disordered students comprised the following:

- 25.2 percent of the total group
- 36.2 percent of the premature etiology group
- 21.9 percent of the rubella group
- 22.8 percent of the RH group
- 16.3 percent of the meningitis group

Considerable attention has been given to the search for hidden behavioral clues and to the discussion of what to do once a determination has been made. "Language is the crucial educational variable in the life of a deaf child" (Vernon, 1969). Elioseff (second 1971 reference) suggested that (1) early language learning in itself may be used as a prognostic indicator of educability; and (2) motiva-

tion, arousal level, and other temperamental characteristics may be closely related to progress in language and, in general, to cognitive development.

Assessment of Temperament, Affect, and Adjustment

A variety of approaches will be discussed in this section.

Curtis and Donlon: Telediagnostic Protocol

A study of 100 evaluations of deaf-blind children (Curtis and Donlon, 1969; Donlon, 1969) indicated that reports on children were written very subjectively, that procedures needed to be standardized, and that more judgmental and subjective statements were made than were objective statements of test results or other objective data. Donlon, in particular, stresses the importance of observational techniques, subjective impressions, and opinions but suggests that a structure for the observations is crucial. As a technique "for enhancement of written reports" and to obtain an objective record of behavior, a videotape protocol was worked out over a period of several years with 20 deaf-blind, congenital rubella, severely handicapped children as subjects. The three aspects of the protocol are as follows:

1. The child is filmed in eight different situations. Purpose, materials, and examiner behavior are described for each situation. The situations sampled are (a) an unstructured situation with no or few materials; (b) a task-oriented situation in which the subject is asked to do something; (c) a stimulus "bombardment" segment; (d) an interpersonal orientation; (e) meal time; (f) bathing, dressing, or toileting; (g) classroom situation; and (h) at play in an informal, social setting.
2. The tapes are assessed by means of a rating protocol form that is used to describe communication, learning, and adjustment as observed in the samples of behavior. The affective section of the rating scale includes curiosity; flexibility; perseverance; attention span; reaction to reward; reaction to punishment; self-concept; energy level; sense of humor; motivation and interest; and self-control.

Tweedie (1974) applied a one-through-nine rating-check to each of the affective factors listed, took two periods separated by several years for rating, and applied a statistical test that indicated

that this method was usable to measure growth over a period of time.

Elzey Approach

Elzey (1970; undated), in a project at San Francisco State College (now San Francisco State University), developed an instrument for "making status assessments" and "measuring growth." This battery included scales in the self-help, manipulative, cognitive, and other areas but centered on presenting an observational rating system for recording of behaviors occurring in a school setting. He describes a "multidimensional time sample observational instrument which would permit ratings of individual children and the adults who came into contact with them . . ." Sample ratings were taken for 15 continuous minutes, with 30 seconds of observation alternating with 30 seconds of recording, using a scale of variables that included the type of experience (for example, none, sensorimotor, manipulative, large muscle, social, cognitive, creative, and other); child involvement level (none, low, medium, high); other direction; person involved; activity level; self-direction; cognitive; and affect (for example, anger-protest, unhappiness, mild happiness, happiness, none, or inappropriate). Variables are given on grids for rating, pairing sets of two. In a trial run, two judges showed better than 85 percent agreement on all but one variable.

Chess Approach

Chess (1971), using the factors extracted from an interview analysis of temperament and mood-type, arrived at a lengthy list of behavioral disturbances that cause serious problems in the home, centering around daily management: sleeping problems; feeding problems; elimination problems; mood (tantrums or flattened affect); discipline (stubborn, destructive); motor activity levels (runs rather than walks); habits and rituals; somatic (vomits at unpleasant odors); social relations (aggressive, autistic); attention; perseveration; high threshold to pain; and so on. Chess's theory suggests that temperament and mood appear to be in part genetically (or congenitally) determined and that interaction with the caretakers may result in a positive or negative interaction, depending upon the temperaments of the caretakers. For example, interaction of an easy-going, quiet parent with a high-strung, hyperactive child can produce difficulties in the relationship. Chess examines by interview the following characteristic behaviors to arrive at a description of the temperament of the

child: activity level, rhythmicity, approach-withdrawal, adaptability, quality of mood, intensity of reaction, threshold of responsiveness, distractibility, attention span, and persistence. However, neither Chess nor Fernandez discusses the application of this theory to an actual deaf-blind child and his or her family.

This framework was used for a short period of time in Perkins evaluations but was abandoned due to the absence of a clear plan for its use and the somewhat cumbersome problem of data collecting. Robbins (1971), listing behaviors observed in a problem-solving situation, suggested that certain observable behaviors were probably more indicative of central nervous system integrity and conducive to mental growth. Aggressive behaviors that were considered to be negative were head-banging, hyperactivity, tantrum, and irritability; positive behaviors were motor-quieting or vocal-quieting, communication about the problem, and refusal to participate. Questionably negative were gazing away or "switching off."

Elioess Response Types

Elioess (1971) attempted to sketch seven response types that she believed were prognostic for educational planning; for example, a self-motivated, interested, language-learning child with normal affect; a vague, slow-to-arouse, sociable, slow-to-develop, and inclined-to-regression child; and a rigid, nonexpressive, highly visual type showing a scattered test profile and poor language capability. This seems to be the type described by van Dijk (1971): hypervisual, high visual memory score on the *Hiskey-Nebraska Test of Learning Aptitude for the Deaf*, failure on reasoning tests, difficulty shifting from one movement to the other in a rhythmic tapping test, body schema difficulty, finger agnosia, and difficulty with speech. The correlation of scores on the Knox Blocks subtest of the *Ontario School Ability Examination* with response types and language difficulty might be informative.

Additionally, Elioess lists behaviors which she intuitively considers as impediments to learning: seizures; seizure-like behaviors (prolonged giggling, frequent staring, and so forth); perseverative behavior; fine-motor difficulties that cannot be attributed to immaturity; stimulus-bound behavior; disinhibition; sudden mood swings; language disorder; gross-motor involvement; disturbed sleeping or eating; and large appetite but no weight gain. Elioess placed heavy emphasis on motivation and

temperamental characteristics as influencing learning positively or negatively.

Summary

For prognosis and for daily management, descriptions of affect, temperament, and general qualities of behavior are vital. Categories of descriptors and some, perhaps complementary, methods of eliciting the descriptions or ratings are available through parent interview, videotape review, or observation in a learning-task-oriented situation. Linking these affective behaviors to educational types, to needs in daily and educational management, to medical considerations for medications, and to prognosis for change and growth seems valuable.

Screening Tests

Several very short tests have been offered for the purpose of screening a large population of children when time is limited or when a quick assessment of the general level of cognitive development of an individual is needed.

Program Placement

Ellisville State School (Lyal, and others, 1972) designed a ten-minute screening test for making objective decisions about deaf-blind candidates for programs in a state school for the retarded and assignment of individuals to categories for program level needs. The test was built on Gesell developmental schedules and includes six items in gross-motor skills, five in fine motor, eight in self-help, seven in communication, and four in socialization. In addition, three items relate to vision and six to hearing. Points are given per item, and a score of five or more in vision and hearing disqualifies the person from eligibility for service. The result would be selection of only deaf-blind or profoundly injured persons who are quite unresponsive to stimuli in general. An ability score is given as is a program priority score that is derived by adding ability score and points for special weighting factors; for example, +10 if the difference between CA and MA is less than five years, +10 if no multihandicaps are present (seizures, hydrocephaly, physical handicaps, and brain damage), and so on. Three program levels are described, and the point scores necessary to qualify for each are given.

Cognitive Function

Elioess (1971) described a short test of cognitive development involving five items in each six-month period from 24 to 48 months. The

purpose was to "uncover the extent of a child's ability to see relationships and remember, learn by observation, anticipate, and plan simple procedures." A testing-teaching approach is taken in the belief that capability is present if the child can learn, retain, and generalize a solution to other materials. Examples of items are the following:

1. Twenty-four months: discriminates round and square pegs; matches parts to the drawing of a face.
2. Thirty months: folds paper in half in imitation; matches several common objects to pictures.

The purpose was to assess the development of a child who showed some skill above eighteen months and to assess cognitive behavior as well as cognitive-perceptual behavior. To do so, Elioseff believes that one must include a range of areas and a range of items and must report basal age.

In an unpublished document, Elioseff (1972) outlined briefly the materials and tasks that she had been using in screening cognitive function of children in state institutions. The test focuses on modes of approach, examination, or experimentation with a particular set of objects for the two-month to 12-month span and elicits particular skills with a definite task request in the 12- to 36-month range. The items and strategies were derived primarily from Uzgis; Gesell, and Cattell. Tasks offered include visual-perceptual, perceptual-motor, imitative, and pattern-making skills. The materials list includes only 11 items.

Kiernan and DuBose (1974) describe a brief test (PIPS or *Peabody Intellectual Performance Scale*) for the purpose of assessing cognitive function. The test design uses 31 tasks, apparently selected from standard tests of intelligence, with three items at each of ten developmental levels ranging from six months to 53 months. The test designers are of the opinion that the chief reason for their judging standardized tests such as the *Ontario School Ability Examination*, *Hiskey-Nebraska Test of Learning Aptitude for the Deaf*, *Cattell Test for Infants and Young Children*, or *Bayley Scales of Infant Development* inadequate is the low degree of stimulus value of many materials used in these tests for children with auditory and visual impairments. Accordingly, alterations were made in task materials. For example, the object to be searched for under a cup is a wobble-toy; cubes are made luminous with Day-Glo paint; puzzle pictures are changed; and green paper instead of white is used for paper folding. Scoring permits calculation of a

basal age and a ceiling mental age. Performance in a correlation study using the instrument on 21 children (ten to 102 months CA) in comparison to performance on either the *Merrill-Palmer Scale of Mental Tests* or the *Bayley Scales of Infant Development* gave an r of 0.95 ($p < 0.01$). A Wilcoxon, matched pairs, signed ranks test was applied: "Scores on the PIPS were found to be significantly higher ($p < 0.01$) than scores on the other measures." They concluded that "the PIPS may be a more appropriate instrument for measuring cognitive development in multi-impaired children than clinical judgments enhanced by available psychological tests . . . multi-impaired children tend to score significantly higher on the PIPS than on the visual standard measures." The *Peabody Intellectual Performance Scale* appears to hold promise as a screening test to use with the visually oriented deaf-blind child.

DuBose (1974) is experimenting with an interesting composite of test items in her *Nonverbal Developmental Screening Inventory*. This test has six test items in each of eight age ranges, from 12 to 17 months to 60 months. The test is unique in organization since perceptual and perceptual-motor items are supplemented by communication items involving naming by signing, object matching, counting, and following commands. The test seems to sample, rather quickly, an important range of behaviors. Scoring is reported as performance in months.

Measurement of Individual Progress

Interest in developing means of evaluating the quality of service to children in any given program and interest in assessing teacher effectiveness led to a particular interest in measuring student progress with objective tools. Many of the assessment tools already discussed can be used for measuring and recording of progress.

The developmental scales can be and are used to measure objectively the progress of the individual by comparing his or her ratings on a particular scale of items with his or her rating at another time. Measure of general learning is possible through comparison of performance on standardized intelligence tests, although little data have been published to suggest what to expect from the individual. Informally, Perkins records suggest that an IQ score gain of 10 to 15 points on performance tests over the school years is very common. Certainly the performance IQ, to indicate growth, should remain reasonably stable as chronological age increases or should itself increase at least up to

the age of sixteen years. Elioseff (1971) reports the use of the *Peabody Picture Vocabulary Test* as a measurement tool in educational programs and as a tool for determining ability to take the *Stanford Achievement Tests*. A *Peabody Picture Vocabulary Test* score above 50, in her opinion, suggests readiness for *Stanford Achievement Tests* (Intermediate II level). A score of 40 suggests readiness for Intermediate I level, but she recommends it only for practice in test-taking. Elioseff reports some achievement test results (1971).

Systems for recording progress of multihandicapped children can be cumbersome, particularly if one is using developmental curricula or developmental listings of activities in a number of different areas. The *Callier-Azusa Scale* provides a summary record of progress by means of a profile line graph; Kootz uses a grid system; and Curtis and Donlon use video tapes repeated from time to time.

The Public School: Learning Disabled and Deaf-Blind

Hearsay, personal observation in Massachusetts, and common sense indicate that there are students in public schools, classes or schools for the deaf, or public school classes for the multihandicapped or neurologically impaired who are partially seeing or seriously hearing impaired, and sometimes, additionally, language disordered or learning disabled.

The literature mentioned at the conclusion of this paper contains essentially no reportable comments on this population, many of whom encounter social, sensory, and learning problems that can be dealt with by consultation with knowledgeable persons and sometimes through program changes. The materials contain no guidelines for referral of children with auditory-visual impairments to public school programs or to schools for the deaf; no guidelines for consultive service to that group of children; and no comment on educational assessment structures for describing such needs, problems, and solutions. Of significance in two recent cases in the Boston area were the primary areas of (1) assessment need; and (2) recommendation:

1. Assessment of actual distance of effective visual plus auditory reception of communication in the classroom
2. Identification of areas of learning disability within the framework of identified generally average intelligence and average school performance
3. Assessment of serious social adjustment difficulties related to multiple factors, including

actual physical limitations as well as emotional-social factors

Assessment for the particular purpose of identifying size of class or size of classroom that the child is sensorily capable of coping with is generally lacking, particularly with regard to public school integration possibilities. Record (1971) examined the ability of four deaf, partially seeing, Perkins students to receive visual communications (speech, fingerspelling, facial expressions, and chalkboard writing) at various distances and attempted to suggest generalizations based on measured distance acuity and relationship to each mode for each student. The study was somewhat naive but interesting and addressed an important question. The issue is pertinent to assessment of educational progress and to decision making concerning appropriate program type.

Tests are used to discover particular learning problems in higher level children, as is apparent in the tests listed on page 139. Such tests would be especially applicable to the deaf-blind population. Van Dijk (1971) implies that specific tests for ascertaining learning disabilities are applicable to many deaf-blind children and would be helpful in deciding upon method of teaching.

The following comment is found in the literature from a West Coast conference (Wright, 1969). It describes two case studies of multihandicapped students in trouble in public school systems, both with auditory and visual impairments of some kind:

So all of you are working with the most deprived youngsters. But I feel that it behooves all of you to use your training and knowledge... which is so much deeper and broader than that of most people in the field of education... to help your less fortunate colleagues understand and accept the children who are not so seriously involved. You are all teachers of multihandicapped children... not just deaf-blind children.

Totally Deaf-Blind Children: Emergent Tools and Techniques; Incidence and Implications

At Perkins currently, 15 of the 84 deaf-blind students (17.8 percent) are totally blind; ten of the 84 (10.9 percent) are totally deaf-blind. Literature from after 1968 does not generally include specific comments on the totally deaf-blind child except that "the congenitally totally blind and totally deaf infant is rare" (Bergstrom, 1971). This low incidence plus the high percentage of congenital rubella etiology in the child population results in a focus of attention on educational assessment tools and interpretive constructs for the partially seeing

deaf or hearing impaired. Yet, often, discussion on the psychological adjustment of the deaf-blind seems to be applying a psychology appropriate for the totally deaf-blind to the partially seeing, hearing impaired, or deaf congenital rubella population. The totally deaf-blind students, though few, deserve consideration because (1) they are individuals with needs and rights; (2) assessment tools are very difficult to assemble, borrow, adapt, or create; (3) norms of development are difficult to develop and are certainly different from those applicable to partially seeing hearing impaired children; and (4) educational needs and methods are very different.

Evaluation Schema

Perkins has been evaluating and educating deaf-blind children for about 18 years and has accumulated considerable data. These data have not been compiled in any way. Due to the lack of other comments in the literature, a few points will be offered here as considerations, from Perkins experience.

Subjective Impressions

Before tests were available on any children in the deaf-blind population, teachers knew very well which ones learned easily, which ones had learning problems, which ones gave poor attention, and so on. Perusal through anecdotal records on totally deaf-blind children and the written reports of adults involved with them reveals interesting choices of verbal descriptors that in themselves clearly suggest very great differences in ease of education of individual students. As was previously mentioned, Stenquist (1974) compiled a list of descriptors from the record of Leonard Dowdy, who became deaf-blind at age nineteen months, is of average intelligence, and is without any additional physical or learning problems. From Dowdy's very early educational years, the list includes the following: "boundless energy . . . fine, upstanding boy full of curiosity and interest . . . charming . . . imaginative." Perusal of another record of a very slow learning child revealed the following: "primitive behavior . . . severe head banging . . . showed neither resourcefulness nor curiosity in feeling objects . . . refuses to cooperate . . . no progress . . . convulsions."

Standardized Test Items: Sources

Stenquist (Robbins and Stenquist, 1967) listed test sources for items that totally deaf-blind persons were able to appreciate and that could be tactually demonstrated to them:

1. Zero—two-year mental level: Maxfield-Field *Scale of Social Maturity for Blind Children* (adaptation of the *Vineland Social Maturity Scale*); pegboards from the *Cattell Scale of Infant Development*; formboard from the *Stanford-Binet Intelligence Scale*
2. Two years to school age: Knox Blocks and knot tying from the *Ontario School Ability Examination*; bead stringing and puzzle blocks from the *Hiskey-Nebraska Test of Learning Aptitude*; items from the 1960 version of the *Stanford-Binet Intelligence Scale* for blind children; sequin formboard from the *Grace Arthur Point Scale of Performance Tests*
3. Young adult scales: *Haptic Intelligence Scale for the Blind Adult*; *Stanford Achievement Tests* (Braille edition)

Development of New Scales and Test Schema

In 1969, work sheets were compiled for use in evaluating the ongoing behaviors of totally deaf-blind children. The work sheets consisted of behavioral, descriptive items relating to compensatory sensory behavior; formal test items sampling cognitive development or approach; and developmental schedules for describing everyday, self-help, behavior. These have not yet been published in any form. Items were created, borrowed from normative data on blind children, and improvised from structures and scales on normal development. The areas sampled are visual behavior, auditory behavior, tactual organization, olfaction and gustation, cup and blocks, spatial relationships, tactile discriminations, and tactual memory.

Nonstandardized test constructs designed from Piaget's observations and theory of development and supplemented by Werner's thinking include the following: test of object recognition, exploration, and meaning; test of perception of similarity and pattern, imitation, and pattern making; manipulation and grasp; nonverbal communication; locomotion; socialization; and self-help skills.

The battery samples behaviors of totally deaf-blind children, with suggested reference age levels assigned to items as they have been compiled from norms for blind children and for seeing/hearing children. In addition to providing ceiling norms, the work sheets are designed for use in assessing behavior on the basis of several stages of cognitive approach.

Summary

A particular need exists to meet the educational assessment requirements of this very low-incidence,

subgroup of totally deaf-blind children by (1) singling this group out in discussion and in research projects; (2) collecting nationally or internationally all available data on such individuals; (3) building a reasonably logical evaluation schema to describe behavior and behavioral changes in areas of educational and life concern; and (4) applying the schema persistently to the assessment of students over a number of years to build an organized body of information.

Concluding Comments

Prior to 1976, educational assessments of deaf-blind children offered only a few tentative beginnings of data collection in an attempt to build norms appropriate to the population and offered valuable but subjective intuitions and observations to guide efforts in differentiating educational needs among the total group. Developmental theory had yet to be applied to the analysis of the deaf-blind child's behavior. Multidisciplinary assessments were unheard of before the early 1960s. Family and community resources and influences were not often recognized in the assessment process itself. Prescriptions for actions based on the results of the assessments were thin and narrow in scope as they related to program needs, choices of educational method, environmental manipulation to promote growth, need for supportive service, and planning for continuing assessment of changing needs.

During the past six to eight years, the efforts of a wide variety of persons and agencies have focused on the educational assessment and programming needs and rights of the congenital rubella population. The result is a true recognition of the range of influences on a deaf-blind child's learning, including home and community influences, physical and biological effects, temperament, a variety of learning differences, and growth rates among the children. Most regions have recognized the necessity for a multidisciplinary approach to the total educational assessment of a child and have recognized the need to develop new tools or to recombine old tools to approach adequately each of the multidisciplinary construct areas. As a result of this examination and exploration of each of the many subareas of assessment carried out by a variety of geographically scattered individuals, a wealth of material is available to guide data collection during the assessment process—developmental scales, normative tests, and innovative procedures. A need exists to organize this material in accordance with an implied but not yet clearly delineated model of the deaf-blind learner—to

expand information related to interpretation of data collected for purposes of immediate prescription and for long-range planning, particularly to build products in which emphasis is on the relationship of assessment techniques to curriculum. The status of those involved in educational assessment of deaf-blind children is perhaps that of a socially focused, self-critical adolescent: energetic, in many ways wise and fresh in terms of thinking, but with energies and knowledges not yet completely integrated nor clearly focused. A need exists to bring together into an organized scheme the specific assessment results available on the national deaf-blind population; the tools and techniques appropriate to each particular assessment phase as outlined earlier; and as much information as is available on interpretation of assessment data as related to vital issues or needs, choice of language mode, methods of teaching concepts, the search for new methods to increase learning, choice of educational settings, and help for parents in understanding how their children think and what they understand and misunderstand.

Clearly, a variety of assessment tools and approaches are necessary because a variety of specific questions must be answered and since a portion of the population is totally blind and deaf; another portion is partially seeing; one portion is on a high linguistic level, using academic textbook materials; and another is on a prelinguistic level, with focus on sensorimotor developments. For some purposes scores are necessary and offer information that can be interpreted into everyday effects. In other cases, profile descriptions that offer developmental age ranges are productive. In other instances, an assessment of the student's achievement with respect to an identified curriculum or outline of developmental steps may prove most useful. At other times specific but intuitively pieced-together information is needed to suggest the answer to a particular problem.

The ultimate outcome of any assessment, no matter what the tools or what the approach; is dependent upon the person who does the assessing. The assessment process is necessarily affected by that person's professional preparation; breadth of experience with a variety of handicapped children; length of experience with children growing and learning over the years; presence or absence of prejudices with respect to educational method; attitude toward life; attitude toward the meaning of education; attitude toward the rights of handicapped children; attitude toward the rights of families; and the inclination of the person or

persons making the assessment to try to relate one area of behavior to another. In the educational assessment of multihandicapped children, a need always exists for objectivity and perspective balanced against an equal need for intuitive action and creativity with respect to the individual.

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Psychoeducational Test Tools Used in Assessing Deaf-Blind Children

LANGUAGE MEASURES

Charles Merrill Preschool Language Scale
Receptive-Expressive-Emergent Language Scale (REEL)
Mecham Language Scales
Inner Language Scale (DuBose)
Nonverbal Communication Scales (Perkins)
Language Acquisition Program for Severely Retarded (Kent)
Wechsler Intelligence Scale for Children: Verbal items (WISC)
Stanford-Binet Scale of Intelligence: Verbal items
Laura Lee Developmental Sentence Scoring
Peabody Picture Vocabulary Test
Hayes Adaptation of Stanford-Binet for the Blind
Locally developed scales of behavior

SELF-HELP SKILLS AND SOCIAL MEASURES

Manual for Development in Self-Care of Multiply Handicapped Children (Peabody)
Adaptive Behaviour Scales
Vineland Social Maturity Scale
Maxfield-Field Scale of Social Maturity for Blind Children
Maxfield-Buchholtz Scale of Social Maturity for Preschool Blind Children
Primary Progress Assessment Chart of Social Development (PAC)
Balthazar Scales of Adaptive Behaviour and Functional Independence
Locally developed scales of behavior

GENERAL MOTOR SCALES

Peabody Developmental Motor Scales
Cratty Test of Body Image in Blind Children
Lincoln-Oseretsky Motor Development Scales
Locally developed scales of behavior

COGNITIVE-ADAPTIVE MEASURES: EARLY DEVELOPMENT

Gesell Developmental Tests
Cattell Infant Scale
Bayley Scales of Infant Development
Preschool Attainment Record
Callier-Azusa Scale
Behaviour Characteristics Progression Chart (DuBose)
BKR Data: Development and Trainability Assessment
Washington Guide
Developmental Checklist (Hart)
Haeussermann Test for Developmental Potential

Psychoeducational Test Tools Used in Assessing Deaf-Blind Children (continued)

COGNITIVE-ADAPTIVE MEASURES: EARLY DEVELOPMENT (Continued)

McCarthy Scales of Children's Ability
Minnesota Preschool Scale
Nonverbal Developmental Screening Inventory (DuBose)
Perkins unpublished materials
Peabody Intellectual Performance Scale (Kiernan and DuBose)
TMR Profile
Michigan Manual for Assessment of a "Deaf-Blind" Multiple Handicapped Child
Locally developed checklists and scales

COGNITIVE-ADAPTIVE NORMATIVE MEASURES

Merrill-Palmer Scale of Mental Tests
Hiskey-Nebraska Test of Learning Aptitude for the Deaf
Leiter International Performance Scale
Grace Arthur Point Scale of Performance Tests
Ontario School Ability Examination
Columbia Mental Maturity Scale
Stanford-Binet Intelligence Test
Wechsler Preschool and Primary Scale of Intelligence (WPPSI)
Wechsler Intelligence Scale for Children (WISC)
Wechsler Adult Intelligence Scale (WAIS)
Blind Learning Aptitude Test
Performance items from 1960 revision of the Hayes-Binet (by Davis)
Goodenough-Harris Draw-a-Man
Detroit Test of Learning Aptitude
Haptic Intelligence Scale for the Blind Adult

PERCEPTUAL SKILLS

Ayres Southern California Test Battery
Frostig Developmental Test of Visual Perception
Bender-Gestalt Test for Children
Purdue Perceptual Motor Survey

ACHIEVEMENT TESTS

Stanford Achievement Tests (Large type and braille editions)
Peabody Individual Achievement Tests

VIDEO PROTOCOLS

Videotape Recording Evaluation Protocol (Curtis and Donlon)

Developmental Areas and Hem Count for the Primary Development Scales Designed for Deaf-Blind Children

Developmental areas	Developmental scales			
	Callier-Azusa (1974)	Michigan (1973)	Mt. Plains	Peabody (1974)
<i>Background information</i>				
General	—	+	+	+/-
<i>Physical condition</i>				
Vision (medical)	—	+	+	—
Hearing (audiologist)	—	+	+	—
Oral physiology (speech pathology or pediatrics)	—	+	+	—
<i>Gross-motor development</i>				205
Postural (head movement, balance, and so forth)	57	85	25	
Locomotion	39	128	167	
<i>Fine-motor development</i>				103
Fine motor (manipulation)	40	54	78	
Visual-motor (special; basic performance test items)	40	85	123	
<i>Perceptual</i>				
Visual: descriptive	33	27	5	
Auditory: descriptive	13	22	15	
audiological		+		
Tactile	16		5	
<i>Daily living skills</i>				
Toileting	28	24	28	
Dressing/undressing	35	56	67	
Personal hygiene	24	36	16	
Feeding	37	76	90	
Daily living aids (glasses and hearing aids)		10	7	
<i>Communication/language</i>				12
General receptive	35			
General expressive	44			
Spontaneous nonverbal				
Social (anticipatory)		15		
Gesturing		11	6	
Pictures		10	6	
Print		6		
Fingerspelling		5		
Oral language (general scale)				
Vocalization/speech expressive	15	30	41	
Receptive		14	33	
Speech Preparation		9	46	
Vocalization/speech characteristics		38		

**Developmental Areas and Hem Count for the Primary Development
Scales Designed for Deaf-Blind Children (Continued)**

Developmental areas	Developmental scales			
	Callier-Azusa (1974)	Michigan (1973)	Mt. Plains	Peabody (1974)
<i>Cognition: General adaptive</i>				30
Attention		10	15	
Imitation		30	12	5
Curiosity		16	10	
Causality			5	
Recognition/use of objects		9	19	
Object concept				5
Constancy		6		
Object permanence				5
Classification of objects		19		
Problem solving		7	5	
Memory (personal belongings, numbers, commuting, pictures, and so forth)		9	36	
Sequencing		5		
Obstacles in path			4	
Representational play			5	
<i>Social development</i>				
Body perception			26	
Self-concept	26			
Socialization	35			
Awareness			27	
Presocial interaction		6	6	
Interaction with adults		34	42	
Interaction with children		5	69	
Interaction with family		10	16	
Behavior in structured educational setting (coop- eration, exploration, self-confidence, discipline, and so forth)		28	37	
Social communication (wants, dislikes, and so forth)			19	

References

- Callier-Azusa—See Stillman.
 Michigan—See *A Manual for the Assessment of a
 "Deaf-Blind" Multiple Handicapped Child*.
 Mountain Plains—See *Developmental Scales*.
 Peabody and DuBose—See Folio and DuBose,
 1974; Brantan and DuBose, 1974; and DuBose,
 1974.

Case Finding and Referral

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Recurring epidemics have resulted in a significant number of cases of maternal rubella during the first trimester of pregnancy and the subsequent birth of infants with partial or total loss of both hearing and vision. Because of the impact on the family and the special needs of these children, it is essential that information reach the parents of these children to inform them of the availability of services for themselves and their children. Federal funds provided under Title VI-C of the Elementary and Secondary Education Act have made special services available to deaf-blind children and their families through ten regional centers.

Information and Case-Finding

The most common approach to dissemination of information to the general public throughout the United States is the use of a brochure that describes services provided to the deaf-blind child. However, mass media are now being used with increasing frequency.

In 1973, Guldager studied the impact of television announcements on attitudes toward handicapped children. His research demonstrated that viewers were most accepting of handicapped children after having seen commercials in which a professional television newscaster authoritatively presented facts about the handicapped and their rehabilitation. A more significant attitude change was noted when the commercials simultaneously showed the children while the narrator described them. Guldager hypothesized that if the narrator were a well-known public figure, an even stronger message would be projected by his or her acceptance of the children despite their obvious handicaps.

Spot announcements for radio and television, varying in length from 30 to 60 seconds, are also

used as a means of increasing acceptance of the handicapped child by the public. Guldager pointed out that if a handicapped child is viewed repeatedly, acceptance can develop in the viewer. Furthermore, such exposure would also increase identification and referral of appropriate children (see the sample scripts on page 148).

The Midwest region distributes information by means of a quarterly bulletin (Collins, 1975). This bulletin is directed to professionals to assist them in the identification of needs of deaf-blind children in Michigan. Waterhouse (1972) has also suggested the following ways of alerting and educating both the public and professionals to the identification needs of deaf-blind children:

1. Individual interviews with key figures in education and rehabilitation
2. Newspaper releases and visits to editors
3. Feature articles in newspapers and magazines
4. Panel discussions on radio and television
5. Circulation of specially prepared films to schools, colleges, clubs, and television stations
6. Organization of regional workshops for professionals in education and rehabilitation
7. Community meetings to reach the general public and to inform neighbors of their local problems and the services available
8. Lectures to medical and paramedical personnel

Glorig (Ireland and Davis, 1965) reinforces the need to alert state, county, and local health departments, welfare agencies, visiting nurses and social workers, and staffs of well-baby clinics and day-care nurseries for underprivileged children. Existing agencies that have already developed avenues of case-finding can be most helpful in recommending approaches they have found successful in the dissemination of information (see

Table I for a list of the types of agencies serving deaf-blind children and the types of services they provide).

Hardy (Ireland and Davis, 1965) recommends establishing a register of high-risk infants who may show the potential for deafness based on "... family background, the mother's pregnancy, conditions for delivery, and events of the immediate postnatal period." The register would list these children to alert obstetricians and pediatricians to follow them with particular care. Hardy contends that children listed in the high-risk register should be examined periodically for possible hearing

impairments. A high-risk register under the direction of a professional person using volunteer assistants is worthy of consideration for case-finding in the future.

Approaches to case-finding vary in accordance with individual state and regional needs. For example, South Dakota, in the Mountain-Plains Region, has initiated a program of case-finding called Project Identification (Woods, 1974), using a comprehensive media campaign. The project focused on reaching all households within the state through major communication networks. Information about the project was also included with all welfare

Table 1
Identification of Referral Sources Serving Deaf-Blind Children

Agencies	Type of Service
Department of Public Welfare	1. Social services 2. Child welfare services
Local Children's Agencies	1. Public/private child placement, including church agencies. 2. Public/private day care centers 3. Hospitals and clinics 4. Educational referrals
Specific to Handicap	1. Blind services 2. Deaf services 3. CP services 4. CC services 5. Retarded children's services

checks mailed within the state. Letters were sent to the state headquarters of each religious denomination, to social and fraternal organizations, and to the National Guard, asking that information about the project be included in their newsletters and periodicals. Information packets were placed in the waiting rooms of physicians' offices and hospitals and included in inservice programs for public health nurses. The most unique approach in the Project Identification campaign was advertising on the sides of milk cartons distributed by a local dairy.

The effectiveness of Project Identification cannot be assessed at this early date. However, the following observations have been made (Woods, 1974):

1. Insufficient financial resources should not be construed as a major barrier to the conduct of an identification survey. Existing resources should be used in a complementary rather than a duplicative effort.

2. Concomitant with the identification survey should be a prevention service program. Justifications for immunization and periodic medical examinations should be articulated.
3. A coalition of agency representatives who are committed to a principle of service to the handicapped can initiate needed service programs.

Agency Coordination in Case-Finding

Some regional center programs have had the advantage of using a case-finding system that predates the funding of the deaf-blind program. For example, the registry of blind persons is required by law in Rhode Island, so almost 100 percent of the deaf-blind population is identified previous to three years of age.

Similarly, the South Central Regional Center has been aided by the Texas Commission for the Blind, which has been functioning for many years. The

latter's approach to identification of deaf-blind children was of significant assistance to the regional center when its case-finding and referral system was developed in 1969. The regional center is now equipped to monitor the flow of children from referral to evaluation (Torrie, 1975).

When regions do not have the advantage of an existing format for case-finding, social workers can be used successfully. An excellent example of a resourceful case-finder in the South Central region (Marquess, 1975) is an Arkansas worker who makes an intensive effort to use every source that might furnish names of children who qualify for services, making personal contact with nurses, parents, and related agencies and writing personal introductory and follow-up letters to these contacts. This worker also keeps in touch with persons who receive more extensive and/or current information, compiling bibliographies and exchanging information. To be effective as a resource person, the social worker must be willing to establish and maintain all possible approaches to case-finding.

New Mexico, part of the Mountain-Plains region, arranged a monthly conference with all state agencies and programs involved in case-finding in an effort to coordinate efforts. Schedules of the travel plans of all participating agencies are distributed monthly. This allows for the coordination of several agencies and more efficient referral procedures. The result is a more efficient use of state resources and personnel as well as increased benefit to families of handicapped children, especially those requiring the services of more than one agency.

Children in the South-Atlantic region who are suspected of being deaf-blind are referred to the South Carolina Department of Education by various agencies, including the Department of Mental Retardation, school districts, day care centers, speech and learning clinics, and any other agencies or organizations associated with handicapped children. The Department of Education works closely with the referring agencies to avoid duplication of evaluation services.

South Carolina uses an evaluation team through the University of South Carolina. The team members represent the following areas: audiology, otology, ophthalmology, speech pathology, educational psychology, and pediatrics (Efron, 1975).

The initial referral, which is often made by the physician, should result in placement. However, final placement should be based on an objective evaluation. Even when the referral is made by other health care systems, a pediatric evaluation is

indicated with substantiation of reports from the ophthalmologist and audiologist to confirm the patient's eligibility to receive services from the deaf-blind program (Rabin, and others, 1974).

Factors That Influence Outcome of Referral

Each geographical and cultural area seems to present unique problems in the identification of appropriate referrals. This may prove to be more difficult in some areas than in others. A report from the Southwest region (Cauffman, and others, 1967) indicated that children from Los Angeles, for example, were more likely to receive prompt attention if they were members of small families of Caucasian or Oriental extraction, with parents who had an education beyond high school and were employed in white collar occupations.

Sparsely populated states present special problems in case-finding and referral because health care in these areas may be limited. Twenty percent of New Mexico's population, for example, was without health care in 1971 (Sanchez and Bynum, 1971), and in some areas of the Navajo Reservation, 50 percent of the children have chronically perforated eardrums (Mortimer, 1973). Fortunately, an experimental teaching program in intra-cultural medicine, as well as other special federal programs, has brought about an increase in health service to the Navajo population, including funds for the identification, training, and education of deaf-blind children on the reservation and in pueblos (Kimball, 1972).

In 1967, Cauffman and others identified factors which influenced the outcome of referrals from a school health service program. The Los Angeles city school system was used because of its large and diversified population and its uniform health service. The results of their research are as follows:

1. Children of parents with a higher income were significantly more likely to receive attention following referral from a school health program.
2. Children of parents who were educated beyond high school were more likely to receive attention than were children of parents with an education less than, or equal to, high school.
3. Children of fathers employed in white collar occupations were more likely to receive attention than were children of fathers employed in blue collar occupations. Mothers working outside of the home did not influence these findings.

4. Children of older parents (fathers over forty years of age and mothers over thirty-five years of age) were more likely to receive attention than were children of younger parents.
5. Children of smaller families (one or two children in the family) were more likely to receive attention than were children of larger families.
6. Children of white and oriental parents were much more likely to receive attention than were children of Negro or Spanish surname parents.
7. Children of Jewish religious preference were much more likely to receive attention than were children of parents having other religious preference.

In relating notifications to outcome of referral, Cauffman made a number of observations. When one notification for treatment recommendation was received, approximately one-half of the parents responded, and an increasing number responded when two or more notifications were sent. Parents contacted by more than one person were significantly more likely to secure attention for their children. This final finding of Cauffman is one of the more significant in case-finding and follow-up. The prior information could prove useful in the intensity of follow-up indicated for those families who may be less likely to be motivated.

Referral to Another Agency

Elling (1974) points out that some of the factors that play a part in the disparity of health services are costs, available manpower, local beliefs, and political factors. The case-finder must be familiar with procedural differences within locations and adhere to the procedures for referral followed by each individual agency. In referring a patient to another agency, the case-finder must obtain release of information forms from the parents to avoid invasion of their privacy and to allow for a minimum of duplication of reporting by the family.

If there is a delay in the transfer of a family to another agency that can serve it more appropriately, the field worker should continue in a supportive role during the interim period. Wall (1964) describes the sudden reluctance on the part of the referring agency to service the patient once his or her family has been referred to another agency. The importance of a close, viable working relationship between agencies can best serve the child and his or her family.

Gruber (1974) proposes using technological advances to coordinate efforts in service related fields.

Efficiency and good human relationships would not be regarded as separate and contradictory features of organized life . . . It is possible to use the newer social techniques and systems to benefit . . . (man).

One technological advancement used for the deaf-blind is a method of data collection. SEARCH, a telecommunications system, is a computer terminal device connected to a central system of telephone lines to provide preventive, diagnostic, therapeutic, and rehabilitative health services. The SEARCH "tracking system" follows consumers who have either medical or social problems, and it follows consumers who are referred by the same organizations. The service provider in such cases may be either an individual or an organization. The system provides for following the consumer into the home and permits comparisons among the data collected from all parties involved in the referral process—referral agencies, service providers, and consumers. A conceptual model for measuring the outcome of referral is shown in Figure 1.

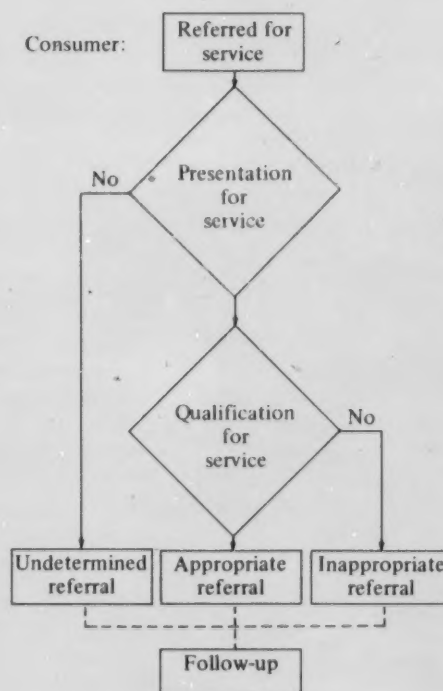


Fig. 1. Conceptual model for measuring outcome of referral

Margin for Improvement

Despite the outstanding national efforts in case-finding and referral demonstrated by the Regional Centers for Services to Deaf-Blind Children, a margin for improvement remains. Suggestions have been made for the coordination of all services and their funding, with a central registry for the children identified, as well as a registry of available certified personnel (Guldager, 1973).

Under the impetus of Project Spin-Off, Southwestern Regional Center, home visitors have assisted more than 300 families of deaf-blind children not previously receiving services, have served as a catalyst between these families and other agencies within their own communities, and have increased community awareness of the needs of these children. Yet, the Department of Health, Education, and Welfare estimates that a number of deaf-blind children are still not receiving services. Case-finding and identification must, therefore, be a continuous, ongoing process in all ten regions.

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Sample Script
Radio Spot Announcement

64	30
Words	Seconds

The Northwest Regional Center for Deaf-Blind Children is anxious to locate all children who have a combination of seeing and hearing difficulties. If you know of any such children, won't you bring them to the attention of: The Northwest Regional Center for Deaf-Blind Children, 3411 South Alaska Street, Seattle, WA 98118 [possible repeat of address] -Phone (206) 464-6694.

Sample Script
Radio Spot Announcement

124	60
Words	Seconds

Do you know any children who are both deaf and blind? The Northwest Regional Center for Deaf-Blind Children is trying to locate all children in the Northwest who have a combination of both hearing and visual problems. The center will assist in diagnosing the extent of the handicap and refer them to programs where they can be educated and trained to the fullest extent of their potential. Aid for families of deaf-blind individuals is also available. If you know any children who you suspect have a handicap of both limited sight and hearing, please contact: The Northwest Regional Center for Deaf-Blind Children, 3411 South Alaska Street, Seattle, WA 98118 or telephone (206) 464-6694.

Sample Television Script
60 Seconds

BACKGROUND-BLACK

LIGHTING-CAMEO

TWO SHOTS OF GEORGE SHEARING AND ROCHELLE SEATED SIDE BY SIDE. GEORGE SHEARING ON HER RIGHT.

ROCHELLE IS HOLDING AND FEELING A TOY STUFFED ANIMAL ON HER LAP.

Hi, I'm George Shearing, and this is a friend of mine, Rochelle.

Rochelle is both deaf and blind, like thousands of other children across the country.

Although she can hear vague sounds and see fuzzy images, she is classified as a deaf-blind child.

But Rochelle is one of the lucky ones.

She is learning many skills which will help her lead a more normal, meaningful life.

Rochelle is receiving these services through a nationwide program sponsored by the U.S. Office of Education.

But for all the thousands this program has helped, there are still thousands more who have not been reached.

Will you help find the others?

If you know someone with combined visual and hearing impairments, please call your Regional Center for Deaf-Blind Children and let them know. You'll help that child turn on to the world. (50 seconds)

INSERT APPROPRIATE AUDIO TAG FOR PHONE NUMBER OF NEAREST REGIONAL CENTER AND/OR TV STATION. (10 seconds)

GO TO BLACK

INSERT APPROPRIATE SLIDE FOR PHONE NUMBER OF NEAREST REGIONAL CENTER AND/OR TV STATION

Infant Stimulation Programming for the Deaf-Blind

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Dramatic changes have taken place within the last five years in the field of early education for the handicapped. Prior to this time, with the exception of a handful of programs scattered around the country, intervention for the handicapped infant did not fall into the province of education but into other professional specialties such as speech therapy, occupational therapy, or physical therapy.

Traditionally, education for a deaf child began when he or she entered a nursery program in a school for the deaf at the age of three or four. The visually impaired infant, depending on where he or she resided, fared a little better. Itinerant teachers did go into homes to provide stimulation for the infant and guidance and counseling for the mother. In general, intervention was focused on individual handicaps: deafness; visual impairment; and mental retardation or cerebral palsy. The word "multi-handicapped" was not used ten years ago in most colleges that were training special educators. Of course, schools for the handicapped did have a class or two in the back corridors or basement for the educational "failures," just as institutions for the mentally retarded had their back wards. But visitors were never allowed to see these children. The rubella epidemic of 1964-65 directed attention to this subculture of the handicapped only because of the number of children that would soon require special education.

The years 1966 through 1968 marked the turning point in special education for the multi-handicapped child. Conferences were convened to study the problem that the "rubella bulge" had created. In November, 1966, the Rubella Birth Defect Evaluation Project reported its findings to leaders from medical, educational, and social service agencies in metropolitan New York. The

clinical manifestations of congenital rubella and unmet service needs among 300 children were described in detail; estimates were presented concerning the true magnitude of the rubella problem in the community. In April, 1967, a parents workshop on rubella, sponsored by John Tracy Clinic, the California State Department of Public Health, and the California State Department of Education, Division of Special Schools and Services, presented parents with current medical and educational information on rubella. With this new knowledge, the parents could play an active role in ensuring that required services would be available for their rubella-damaged children. In May, 1967, a conference was convened through the collaborative efforts of the Rubella Project, the New York State Commission for the Blind and Visually Handicapped, the New York City Board of Education, and five voluntary social agencies to alert a wider audience to "A Community and Family Crisis: The Congenitally Impaired Child: New Approaches to Early Childhood and Education." At about the same time, a special study institute for the multi-handicapped, sponsored by the California State Department of Education, met to assess the impact this population would have upon the educational and training institutions.

In 1968, Congress enacted Public Law 91-230, Title VI-C, "Centers and Services for Deaf-Blind Children," to be administered by the Bureau of Education for the Handicapped (BEH), U.S. Office of Education. The rubella victims were already four to five years old. Identification, evaluation, referral, and placement in educational programs were the major thrusts for this school-age population. The first programs did not qualify as infant stimulation per se. However, the Deaf-Blind Cen-

ters Act (the first passed after creation of BEH) established a legislative basis for delivery of educational services to infants, because it did not have a lower limit of eligibility. Subsequently, more emphasis on early education resulted in passage of the Handicapped Children's Early Education Act, which authorized the establishment and operation of model early education projects. This act, which created the First Chance Network, has not focused on the deaf-blind. Deaf-blind infants are receiving services primarily within the framework of the ten Regional Centers for Services to Deaf-Blind Children.

By June, 1969, sufficient progress had been made for convening a special study institute to consider the "Effect of Preschool Service for the Deaf-Blind." Reports were presented that described operational diagnostic and evaluation teams, teacher training efforts, and preschool programs for the deaf-blind child.

The rubella crisis may be over, but this does not mean that rubella has been eliminated. The Center for Disease Control (CDC) has reported 237 cases of congenital rubella since 1969 (Modlin, 1975). Forty-five percent of these cases were referred to CDC through the Rubella Project. Since the Rubella Project serves an area which includes 5 percent of the national population, it is reasonable to assume that there are many more cases that have not been identified to the CDC. In addition, as described elsewhere in this volume, other diseases produce the combined visual and auditory impairment.

The purpose of this paper is to review the state of the art in early educational services for deaf-blind infants and young children. These programs frequently are referred to as infant stimulation programs, but this title is far too restrictive to describe the wide range of activity which takes place in an adequate program for these infants and their families. This presentation consists of two major parts: (1) a rationale for early intervention and (2) a description of the components of a full service program.

Rationale for Early Intervention

Presently accepted concepts of child development, as they apply to the deaf-blind child, may be viewed for simplicity as follows:

1. An infant born biologically intact can develop to full genetic potential if his or her environment is normal-experiential.
2. An infant born biologically intact will demonstrate developmental attrition (failure to

achieve his or her genetic potential) if he or she is environmentally deprived.

3. An infant born with biologic deficits such as deafness, blindness, brain injury, or some combination thereof, is at risk of developmental attrition equal to or greater than the biological insult.

The rationale for intervention programs for such children is a belief that compensatory or alternative experiences may prevent or minimize this attrition. This belief is now based on decades of laboratory and clinical observation. Unfortunately, none of these data as yet provide documentation of the impact of early intervention on life outcome of the deaf-blind child and his or her family. However, this review has attempted to select observations which may have bearing on the issues at hand.

Background Information

From before the turn of the century through World War II, two viewpoints in the behavioral sciences prevailed: the assumption of "fixed intelligence" and the assumption of "predetermined development" (Hunt, 1969). The human infant was viewed as a passive, dull organism whose development was entirely mediated by inflexible internal neurological and biological events.

Acceleration of development . . . is typically an inherent biological characteristic of the individual, most probably hereditary in nature. There is no convincing evidence that fundamental acceleration of development can be readily induced by either pernicious or enlightened methods of stimulation (Gesell, 1928).

Succeeding scientific studies have pointed out the deficits in the nature-nurture controversy, a thesis first promulgated by Canton in *Hereditary Genius: An Inquiry into Its Law and Consequences* (1869). Although debate still continues, the nature-nurture controversy is now passe among many professionals. In actuality, acceptance of the significance of genetic factors does not minimize the importance of asking questions: Is shaping of the deaf-blind infant's environment likely to be of value, and if so, when and how?

In 1935, Piaget presented a picture of the development of intelligence as continuous transformation in the organizations or structures of intelligence. He presented intelligence as an adaptive interaction between the organism and the environment. On the basis of these concepts and supporting observations from many other investigators, it should be possible for the educator to shape the deaf-blind infant's environment to provide him or

her with experience that will foster positive growth and development (Hunt, 1961).

Furthermore, we now know that the human newborn infant is a responsive organism (Lipsett, 1971).

We know that he sees because he follows objects and geometric patterns with his eyes. We know that he hears from the fact that when we administer certain sounds, the baby's activity increases, his heart rate accelerates, and his respiration is momentarily quickened. We know that he is sensitive to the touch of objects on his face, particularly around his mouth, because he tends to turn his mouth toward the locus of contact. We know that the inside of his mouth is sensitive to touch, because he latches on to some objects placed there, while he tends to thrust others out with his tongue. We know that he has taste sensitivity because he sucks more vigorously and in longer bursts to some fluids than he does to others, and indeed he stops sucking altogether when some nonsweet substances are delivered to him. We know that he can smell, because a polygraph record reflecting motor activity, heart rate, and respiration look different when he is presented with some substances than when he is presented with other substances or no substance at all. Although the human newborn cannot articulate for us what he senses and feels, he can nevertheless get the message to us through his systematic, congenital responses to stimuli which appear in his environment.

Lipsett believes "that it is precisely the orderly nature of the congenital response repertoire of the human newborn that makes this organism a likely candidate for the acquisition of learning at least as soon as birth." His experiments with two-to-four-day-old infants demonstrate that these infants are capable of learning and are susceptible to both classical and operant conditioning. Although these experiments did not involve deaf-blind infants, they gave solid clues for answering the first question: "When is shaping of the deaf-blind infant's environment likely to be of value?" The answer is probably from the first days of life!

Visual impairment, severe and profound hearing losses, severe mental retardation, and severe neurological dysfunction can often be detected in young infants. Complicating defects and milder degrees of auditory and visual impairment, cerebral palsy, or mental dysfunction cannot be detected as readily in this age group. Furthermore, we cannot predict from an infant's behavior what his or her future performance will be. The correlation between infant intelligence tests and future performance is poor, except at the very low end of the scale. Even this may be misleading because the infant's later performance can be affected profoundly by the

environment. Studies have shown that there is a relationship between an infant's developmental status and socioeconomic status. Retarded infants are more vulnerable to the adverse effects of their environments, even though there is a poor correlation between social class and test performance in infancy (Willerman, 1970). As Lipsett documented, the infant is not a powerless organism. To some extent, the infant is able to shape the environment through his or her ability to learn and through his or her temperament. Nevertheless, he or she is still a helpless organism because of the inability to control the innate biological resources or the environment into which he or she is born.

The saying that "poverty begets poverty" cannot be overlooked. A basic relationship exists between illness and educational failure. In addition, because the infant is dependent, the caretaker plays an instrumental role in shaping early learning. However, the lasting effects of early care or noncare and the relationships between deprivation and later performance have not been fully established.

Role of Early Deprivation

What role does early deprivation play in the attainment of experience? We know from longitudinal studies of biologically intact infants that early intervention with orphaned infants did alter their future life-style and that the intellectual gains these children made in early or middle childhood were maintained in adulthood (Skeels and others, 1972). Deaf-blind children are multisensorially deprived from birth. Other factors such as poverty and malnutrition and additional physical defects often add to the burden. Their deprivation is continuous and probably cumulative. To intervene effectively or to know what is relevant to the planning of content and curriculum for infant stimulation programs, one must first know what the deaf-blind infant has had limited access to or has been growing up without.

A great deal of what is known about infant development comes from the initial testing of specific hypotheses on lower animals. Many of the principles emanating from animal research have application and implications for human education. Although what may be true for chimpanzees or chicks may not necessarily apply completely to human infants, studies of sensory and maternal deprivation that have been done with animals serve as a guide to understanding human development. "In fact, it is fair to say that many of the important changes in our views of intelligence that have come

about within the last decade or so can be attributed to new insights growing out of animal research" (Mason, 1970).

Visual Deprivation

The knowledge that the human infant is responsive to such stimuli as shape, pattern, size, and solidity as opposed to only light, color, and movement grew out of studies with chicks at the University of Chicago. Experiments by Fantz (1971) indicated that chicks have an innate ability to perceive shape, three dimensionality, and size. The chicks used these skills meaningfully to select objects the size and shape of grain or seeds. A visual interest test was given to 30 infants whose initial ages ranged from one to fifteen weeks. The total time the infants spent looking at the test patterns correlated directly with the complexity of the patterns. The differential response to patterns occurred at all ages, indicating that it was not the result of a learning process. Similar results were obtained by a Swiss pediatrician, F. Stirnimann, who studied infants ranging in age from one to fourteen days. Patterned cards were more interesting to the newborn infants than those with plain colors (Fantz, 1971). When 49 infants from four days to six months of age were tested with three flat objects the size and shape of a head, the results were the same throughout the age range; infants looked most frequently at the "real" face, somewhat less often at the scrambled face, and ignored the control pattern. The real face was selected consistently by the younger infants. The infant's preference for the face pattern might relate to the specific importance of the human to the infant, just as the chick is able to pick out the shapes that look like grain.

With maturation, the human infant's visual acuity increases. However, the effects of learning on visual perception are more subtle than acuity alone and must be understood for the educator to deal effectively with the visually impaired infant.

Depriving animals of patterned visual stimuli for a period after birth impairs their later visual performance, especially the ability to perceive form. Not only is learned behavior vulnerable, but innate responses are affected as well. Chicks kept in darkness for several weeks after birth lost the ability to peck at food. Reisen (1950) demonstrated that there are critical periods in the development of form perception. Three infant chimpanzees were reared in a dark room from birth under the following conditions: one was kept in complete darkness for the duration; the second was

allowed an hour and a half of light daily through a white plexiglass mask that admitted only diffused, unpatterned light; and the third was allowed an hour and a half of patterned light each day so that the animal could observe the edges of the crib, variations in pattern introduced by movements of the body and limbs, and the accompaniments of bottle feeding. When the chimps were tested in the light at the end of seven months, those reared in complete darkness or with exposure only to diffuse light exhibited an extreme degree of visual incompetence. They could not fixate upon either a stationary or a moving object. However, with subsequent visual experience, the latter chimps acquired visual competence much more rapidly than the chimps who had been totally deprived of light. In sharp contrast, the chimp allowed an hour and a half of patterned light each day was able immediately to fixate on a person, visually pursue an object moving across the visual field, and visually pursue the feeding bottle. This chimp did exhibit initial avoidance of strange objects. The behavior was extinguished in two days, while it took four months for the other two chimpanzees to "learn to see." In addition, the behavior of the chimp that had been allowed only an hour-and-a-half of patterned vision a day was barely distinguishable from that of the normally reared chimpanzees.

Additional experiments by Fantz indicate that monkeys kept in the dark for a shorter period of time are usually able to show good spatial orientation in a few hours or days. In addition, the monkeys demonstrated normal interest in patterned objects, whereas the animals deprived of light for longer periods seemed more interested in color, brightness, and size.

... there appears to be a complex interplay of innate ability, maturation, and learning in the molding of visual behavior, operating in this manner; there is a critical age for the development of a given visual response when the visual, mental, and motor capacities are ready to be used and under normal circumstances will either show the response without experience or will learn it readily. If the response is not "imprinted" at the critical age for want of visual stimulus, development proceeds abnormally without the visual component. Presented with the stimulus later on, the animal learns to respond, if it responds at all, only with extensive experience and training (Fantz, 1971).

Inferences that are relevant for infants born with congenital rubella cataracts can be drawn from these studies. First, one can infer from these studies and from experience that the infant with

bilateral cataracts is able to perceive color and brightness. These infants are similar to the chimp raised behind the white plexiglass mask. After completion of successful cataract surgery, they should be able to "learn to see" and to develop form perception. Second, congenital cataracts mature at variable rates. Some do not mature until the third or fourth month of life, and it is not uncommon for the mother to be the first person to detect the cataract several weeks after the newborn is discharged from the nursery (Weiss, 1972). Therefore, these infants may have a variable visual experience prior to the appearance of the cataracts. Whether this brief visual experience during the first month of life has an effect on their later learning ability is not known.

Depriving chimpanzees of their sight affected their ability to relate meaningfully to the environment and rendered them functionally retarded. When their sight was restored, the chimps were able to make up this developmental lag with training and experience. The infant with cataracts, like the chimps, is deprived of the opportunity for incidental learning. Subsequently, the infant may learn to see but without encouragement will be retarded in his or her ability to sit, stand, creep, or walk.

The research of Held and his associates (1963, 1965, 1967) points out the interrelationship and interdependence of sensory and motor functions to the development of motor coordination. Of particular concern is the role of motor feedback to the development of visual-motor function. The effect of environmental interaction on the development of visual-motor coordination was demonstrated in an experiment that involved actively and passively transported kittens. Eight pairs of kittens raised in the dark were given a brief daily exposure to light. One of the paired kittens walked freely around a circle pulling a carriage that contained the other kitten. Visual stimulation was the same for both kittens. Subsequent testing indicated that the active kittens were superior to the passive kittens in tests of spatial localization. The active kittens blinked at approaching objects, extended their forepaws to ward off collision, and had normal depth perception. The passive kittens did not demonstrate this behavior until they were allowed to run about freely for a number of days (Held and Hein, 1963; Held, 1965).

Visual-motor defects also appeared in animals allowed freedom of movement but deprived of seeing their hands. Macaque monkeys raised from birth to an age of thirty-five days were inferior to

the control monkeys of the same age in ability to reach accurately for objects. Accuracy and performance increased within hours after the monkeys were given the opportunity for "self-instruction." Precision occurred because the monkeys were allowed to view their own hand movements (Held and Bauer, 1967). Deprivation involving motor-visual feedback appears to be reversible, unlike the more severe deprivation, which involves vision alone.

Hypotonia is a common clinical manifestation among visually impaired infants. On the basis of the preceding studies, it is reasonable to suspect that delayed motor development is attributable, at least in part, to lack of visual stimulation. Impeded early exposure to gross motor activities leads to later impaired gross and fine motor coordination. This is true for the congenitally blind as well as the visually limited infant whose central nervous system may be otherwise uninvolved. The problem is compounded regularly for the infant who is deaf-blind due to congenital rubella because primary neurologic impairment is common in this disease (Cooper, 1969).

Auditory Deprivation

Variables such as socioeconomic level, the speech environment, and intelligence influence the development of expressive language in the normal infant. Studies have shown that the normal infant has the receptive capacity to discriminate among and respond selectively to auditory signals (Eisenberg, 1966). Cardiac and motor responses were studied to determine whether individual response to stimuli changed with the intensity of the stimulus (Steinschneider and others, 1966). Results indicate that the cardiac responses of newborn infants differed with the intensity of the auditory stimulus. Thomas (1963) was able to demonstrate that infants between the ages of one and four months were able to discriminate between the voiced and voiceless stop consonants *b* and *p*. Whether one believes that language is innate, unfolds, or is acquired, the human infant does evidence the capacity to attend to sound discriminatively.

Although there is no universally accepted theoretical basis for language acquisition, there does appear to be a "schedule of involvement in which apparently one set of events sets the stage for a subsequent set, and so on" (Lenneberg, 1967). This has been demonstrated even in children whose developmental sequencing is obviously delayed. In children with Down's syndrome, the sequential

emergence of language remains undisturbed with the exception of articulation of phonemes. Intellectual limitation does influence the qualitative aspects of their language output. Nevertheless, the child with Down's syndrome progresses through normal stages before expressive language development is arrested.

The breadth of the deprivation to a child who suffers biologic insult to the auditory nerve is enormous. Nevertheless, early intervention programs for deaf infants have shown that it is possible for the profoundly deaf child to develop good oral language skills. This is particularly remarkable because the eye is slower in temporal integration than the ear. Even the most proficient lip-reader cannot identify more than 40 to 50 percent of articulated phonemes. A deaf child who does not begin intensive language training until the age of three or four is already "at an age when other children have fully mastered this skill and when perhaps the most important formative period for language establishment is already on the decline" (Lenneberg, 1967).

The task of learning language even for an intact deaf child is monumental. Most deaf-blind children have either mental or neurological dysfunction. Therefore, to expect processing of verbal language, with visually limited eyes and a biologically injured brain, is probably unrealistic. Many of us have learned that these attempts at teaching speech were for many children merely piling deprivation onto already existing privation.

Maternal Deprivation

The physician, psychologist, and educator or counselor of the deaf-blind cannot overlook the similarities between these children and maternally deprived, biologically intact human infants and infant monkeys. The central issue, though, is identifying the specific environmental factors that influence adequate development. By identifying what is missing, the studies of infants in institutions give insight into the social and nonsocial stimulation needed for adequate cognitive and social development. Nowhere is the impact of infantile isolation and maternal deprivation more evident than in the work of Harlow and his associates (1959, 1963, 1971). The results of their experiments with deprived monkeys provide additional perspective in our attempt to understand the privation of the deaf-blind infant.

Spitz' study (1945, 1946) of "hospitalism" in two contrasting groups of infants confined to institutions demonstrated the effects of stimulus

deprivation on the human infant. One group of 61 infants lived in a foundling home. The second group of 69 infants lived in a nursery attached to a penal institution. The infants in the foundling home received very little stimulation after their mothers stopped nursing them at three months of age. The nursery infants were cared for by their mothers on a daily basis during the first year of life. The developmental quotient for the 61 children in the foundling home dropped progressively during the course of the infants' first year from a mean of 124 the first four months to 72 for the last four months. In contrast, the developmental quotient for the nursery group was 101.5 for the first four months and 105 for the last four months. Spitz attributed the drop in developmental quotient for the foundling babies to the lack of mothering. Spitz also described a syndrome, which he called "anaclitic depression," in which the infant manifests weight loss, decline in developmental quotient, increased susceptibility to infection, weepiness, and withdrawal. Spitz also attributed this phenomenon to lack of mothering.

Upon closer scrutiny, not all of the children whose mothers were removed developed this syndrome. The affected children were all between six and eleven months of age when separation occurred. Spitz felt that "the factors leading to the development of anaclitic depression in human infants involved separation from a mother with whom the infant had developed a strong dependency and placement in a stimulus restricted environment without adequate mother substitutes" (1972). The human infants then became inept because they lacked the motivation to interact with the environment.

Provence and Lipton's (1962) detailed study of infants institutionalized at birth presented further evidence of the effects of stimulus deprivation:

... Two observations are relevant: one is the infant's low impulse to approach, reach out for, and make contact with other people, his or her own body, and with toys. The other is the poor capacity to modulate the motor impulses to produce a smooth motor movement. If one accepts the notion that some of these are behavioral manifestations or derivatives of the psychic drives, these observations suggest a disturbance in the normal regulation and discharge of drive energy, and point to the importance of adequate maternal care in such regulation.

Harlow and Zimmerman's (1959) classic studies of monkeys deprived of their real mothers demonstrated another aspect of the effects of deprivation that has relevance to the deaf-blind. These investigators separated infant monkeys from their real

mothers and substituted terry cloth and wire mesh mothers in their place. Both groups learned to adapt to their new mothers for feeding. However, the terry cloth mothers, because of their soft, textured surface, provided more comfort to the infants than that provided by the wire mothers. When the monkeys were placed in an unfamiliar playroom without the cloth mother present, crouching, rocking, and sucking increased sharply. The monkeys would rush to the center of the room, where the mother was customarily placed, and then run from object to object screaming and crying all the while. When the cloth mother was present, the monkeys would immediately run and hold on to her tenaciously. Once the monkeys became secure, they would begin to explore and manipulate objects in the environment, using the mother as a security base. This experiment demonstrated that contact comfort was far more important to the infant monkey than nutritive sucking.

Harlow and Zimmerman repeated the study with monkeys raised exclusively with wire mesh mothers. The monkeys were placed in an unfamiliar playroom with the wire mother present. Instead of clinging, the monkeys engaged in convulsive jerking and rocking movements "similar to the autistic behavior characteristic of neglected children who are usually in and out of institutions." In this case, the resemblance between the aberrant behavior of the monkeys deprived of their mothers and that of many deaf-blind children is not difficult to see. However, it would be incorrect to assume that Harlow's observations imply that parental neglect is a significant cause of infantile autism. The observation that congenital rubella can produce this poorly understood disorder suggests that primary brain injury is the most likely cause of the problem (Chess, 1972).

Many deaf-blind children require long hospitalization during infancy. This event is even more isolating for these infants than for those who are sensorially intact. Self-stimulatory and stereotypic behavior patterns established in the hospital frequently are reinforced when the infant returns home to rejecting parents.

When monkeys are separated from their mothers at birth, their behavior appears to be similar to that of disturbed, self-abusive, deaf-blind infants and children.

... The laboratory-born monkeys sit in their cages and stare fixedly into space, circle their cages in a repetitive stereotyped manner, and clasp their head in their hands or arms and rock for long periods of time. They often develop compulsive habits, such as pinching precisely the

same patch of skin on the chest between the same fingers hundreds of times a day; occasionally such behavior may become punitive, and the animal may chew and tear at its body until it bleeds. Often the approach of a human being becomes the stimulus to self-aggression (Harlow, 1963).

Additional studies on contact comfort reflect the strong parallel between the behavior of deaf-blind infants and Harlow's deprived monkeys. Seay, Hansen, and Harlow (1962) studied the effects of maternal separation upon two pairs of sibling monkeys ranging in age from five-and-a-half to seven months. The four monkeys were separated from their mothers by means of plexiglass panels, which permitted only visual and auditory contact. Although the sibling monkeys were paired for this experiment with free access to each other, they still huddled up against the barriers as close as possible to the mother on the other side. As a consequence of this contact deprivation, the young monkeys exhibited not only frustration and heightened drive behavior but also a specific syndrome of emotional disturbance.

Harlow investigated the concept of "critical periods" in the infant monkey's development and found that monkeys who underwent six months of isolation were rendered permanently inadequate, whereas shorter periods of isolation, perhaps 60 to 90 days or even more, were clearly reversible.

If the animal is isolated from birth for an extended period, as has typically occurred in the research on monkeys, the observed effects are due purely to stimulus restriction and include ... an initial reaction of anxiety and withdrawal followed by hyperactivity, diffuseness, and general ineptitude in all spheres of activity—intellectual, emotional, and social ... the undifferentiated emotional reaction characteristic of early restricted animals and their irresponsiveness to training result in part from the fact that the animal has never developed the normal attachment to a mother which functions both to direct and differentiate response. Lacking this special motivation and training demand, the animal is less susceptible to learning. We see here that the stimulus restriction can result not only in drive deprivation; it may actually preclude the development of a drive necessary for the animal's normal physiological growth (Bronfenbrenner, 1972).

Two issues have been identified which are major to early intervention with the deaf-blind. The first issue is the concept of critical periods for the establishment of attachment. The critical period for the impact of stimulus and drive deprivation in monkeys was between two and six months of age. Continuous isolation during this four-month interval leads to irreversible damage. The critical period

for attachment in the human infant occurs later in infancy. Although the boundaries of and for this critical period remain open-ended, attachment bonds are established by eighteen months. The absence of a caretaker or disruption of the mother-infant dyad may permanently impair the child's capacity to be independent and to form lasting relationships in adulthood.

Fraiberg has demonstrated that the blind (but otherwise intact) infant is capable of forming healthy attachment bonds. These infants develop differential smiling and stranger reactions at approximately the same age as do sighted children. In Bayley (1971), attachment is an even more complex issue in relation to the deaf-blind because the central role that both vision and hearing play in the establishment of human object relations is considered. In an unpublished study (Appell, 1974), the progress of three groups of multihandicapped children enrolled in a nursery program for the deaf-blind was compared for four target areas: language development, motor performance, adaptive skills, and affective behavior. The three groups entered the program at different ages; the first group at age one, the second at age three, and the third at age five. The average stay in the program was two years for each group. The only group that demonstrated noticeable change in the area of affective behavior and the establishment of object relationships (extinguishing self-stimulatory and various ritualistic behaviors) was the children who entered the program when a year old.

The second issue is the significant role motivation plays in early infant learning. The infant becomes oriented to the environment by smiling, vocalizing, and reaching out to people. In addition, the manipulation of objects can be self-reinforcing for the infant. Adult responses to the infant play an important role in developing and maintaining social responsiveness. The isolated monkey and human infants became inept because they lacked the motivation to interact with the environment. This illustrates the interrelationship of inanimate and animate stimuli to the infant's cognitive development. The influence of the infant's temperament on the quality of these interactions is also important. An active and responsive infant evokes more positive responses than one who is lethargic, withdrawn, or chronically irritable. This phenomenon is particularly relevant with regard to infant stimulation programming for the deaf-blind. The cry of a brain-injured infant often is painfully shrill and piercing. The quality of the sound may be so

unpleasant that even hospital personnel tend to maintain minimum contact with these infants.

The Maternal Bond

To summarize, the normal infant needs a wide variety of stimuli, support, and encouragement to gain independence. The handicapped infant needs even more practice and security if he or she is to be mobile and independent. The mother or her surrogate is instrumental in mediating a great deal of the stimulation the infant receives. The caretaking role itself provides the infant with a constant source of visual, auditory, tactual, kinesthetic, and proprioceptive stimulation, all of which are intrinsic to cognitive development.

...there is an enormous influence exerted by the caretaker, be it mother, teacher, whoever the person who is usually there. It is the role of an accessible model, or as John Bowlby (1969) has recently proposed, is it that the caretaker provides a basis for reciprocal relationship that allows the infant to develop rules for getting on generally? While the importance of reciprocity is universally granted, most contemporary theories of intellectual or cognitive development leave the mother out of account (Bruner, 1970).

We have examined the effects of early maternal deprivation upon the monkey and human infant. However, what effect does separation of the infant have on the mother?

Harlow (1963) studied mother monkeys who were allowed to see and hear their infants but were not permitted any tactile contact. After a period of two weeks, the amount of time the mothers spent viewing their infants decreased rapidly. What is particularly relevant is that deaf-blind infants usually are at high risk because of prematurity or illness at birth. In the Western world, premature infants are separated from their mothers in the first days after delivery and in some cases may remain separated for a period of up to seven months (Klaus and Kennell, 1970).

Although we are able to index the attachment behavior of the human infant (Ainsworth, 1967), the process by which attachment bonds are formed between mother and infant is unknown. On the basis of careful observations of early postpartum events, Klaus and Kennell (1970) have suggested that what happens in the period immediately following delivery may be critical to later maternal behavior. These investigators have focused on the questions of how affectional bonds between human mothers and their infants are built and how this process may be altered or distorted temporarily or permanently. They have demonstrated

that the human mother moves through an orderly behavioral progression which involves tactile exploration of her newborn infant. Eye-contact with the infant also appeared to be an important aspect of this progression. Klaus and Kennell hypothesized that the variable that determines whether or not the mother will suffer from a "series of disorders of mothering" is separation from her infant in the early newborn period. This hypothesis is supported by the high incidence of premature infants who return to the hospital because of "failure to thrive."

In further studies by Klaus and Kennell, sets of mothers who had early contact with their infants were compared with those who had late contact with their infants. Mothers who had late contact were less skillful in caretaking and did less looking at, holding, and caressing the infant.

The results of a two-year follow-up study (1975) indicated that the early contact mothers were more aware of the growing needs of their children than the other group. In addition, the quality of verbal interchange between the early contact mothers and their children was richer in content and complexity of ideas than that of the late contact mothers. The authors concluded that the attention of the early contact mothers to their infants "could have significant bearing on the child's behavior as well as on the child's future cognitive and linguistic development (Ringler and Kennell, 1975).

Infant Stimulation Programs

The preceding observations provide justification for intervening as soon as deaf-blindness is suspected to compensate for the overwhelming privation these defects produce. This section discusses the adaptive substitutions that are necessary to minimize the potentially devastating consequences of these tragic biologic insults.

Intervention programs for deaf-blind infants can be fully effective only as one component of a broad-based service delivery system. The elements in this network include (1) early detection of disease; (2) medical diagnosis and treatment; and (3) infant stimulation, including parent and family education and counseling.

Because these activities are continuous, interdependent, and overlapping, organization, coordination, and priority setting are essential to their success.

Early identification with medical and educational intervention and early parent training may make the difference as to whether the deaf-blind child enters the mainstream of special education or

enters an institution for the mentally retarded. Unfortunately, the necessary coordination and cooperation is too often lacking, and valuable time is lost in bringing care to the deaf-blind infant and his or her family. Nevertheless, the willingness of the regional deaf-blind centers to support and transcend the boundaries between public and private service delivery systems has led to improved programming during the first few critical years of the deaf-blind child's life. Hopefully, this example will serve as a stimulus and a model for early intervention for all severely handicapped infants.

Generic Barriers to Early Intervention

Early educational intervention requires early detection of disease. Initial determination of an infant's clinical status is usually made by a physician. A potential problem may be suspected prenatally because of maternal disease: for example, rubella, cytomegalovirus infection, or Rh sensitization (known genetic predisposition), or other high risk factors in pregnancy. Diagnosis may occur as early as birth if the infant is observably sick or in the newborn nursery during the first days of life. Frequently, detection does not occur until after discharge from the hospital, when the mother suspects that the infant is not behaving normally. She may even see cataracts or wonder whether her child is deaf. The first gap in the delivery of early service may be encountered at this point if the mother, a well-meaning relative, or even the physician chooses to ignore the infant's abnormality, attributing it to the infant's early age.

Deaf-blind infants have complex medical needs. However, the physician often forgets that these infants also have complex educational needs. Two major problems occur at this point. The first is the isolation of the infant during hospitalization for illness or surgery. This is an ongoing problem which affects the older deaf-blind child as well. Too few hospitals have the staff to stimulate these infants and children. They usually are excluded from pediatric recreation programs. Furthermore, many deaf-blind infants have other overt and sometimes life-threatening medical conditions which justifiably require tremendous attention from the staff of doctors, nurses, social workers, and therapists at the hospital. Educational programs often tend to ignore the hospitalized older child, because no interagency communication takes place during the child's hospitalization.

The second problem is the physician's failure to seek educational resources for the deaf-blind infant. Although physicians have begun to recog-

nize the importance of infancy as a period of effective and cognitive development, most are still unaware that educational programs exist and are of value for the multihandicapped infant and young child. Too often referral to an educational program is a serendipitous event. Delay is not the sole responsibility of health professionals. Gaps and fragmentation in the education and social service systems compound the problem. In addition, the educator frequently is so overwhelmed by the disease aspects of deaf-blindness that he or she loses perspective, ignoring important assets which the infant, his or her family, and environment may possess. These assets are the foundation on which an educational program must be built. A partnership between health, education, and family services is essential to create an effective program that defines and expands the functional capacities of the deaf-blind child.

Settings for Infant Stimulation

Infant stimulation programs for the deaf-blind have been explored during the past decade most frequently in three different settings. The first setting for an infant program is the hospital or medical center. Typically, the staff for this type program is broadly interdisciplinary. Special educators such as the occupational therapist, audiologist, psychologist, and social worker are usually integral components of the program. Available on a consultant basis are a full range of medical specialists, including a pediatrician, neurologist, psychiatrist, cardiologist, ophthalmologist, otologist, nurses, and nutritionists. An individualized plan for both the infant and the family uses the services of the various team members in a coordinated manner. The hospital-based program has the following advantages: (1) reduction of the detrimental delay between detection, evaluation, and service for the infant and his or her family; (2) decreased fragmentation of services; (3) improved follow-through on recommendations from medical, social service, and education team members; and (4) continuation and continuity of care to the infant and his or her family upon entering the hospital for inpatient services. Although the infant program does not guarantee it, placement of such a program in a medical center for the deaf-blind enhances the likelihood that diagnosis, evaluation, and treatment will be ongoing and interdependent.

The second setting for an infant program is a school for the deaf and/or blind which has decreased its age requirement or a private agency. The approach used is similar to that of the

hospital-based program, except that medical and related ancillary services are usually not on site. This places an additional burden on the program director or social worker to ensure that services are coordinated and that neither information nor the infant and parents are lost in the complex service maze. This maze, which can dampen the ardor of an experienced professional, can easily frustrate already depressed and frightened parents into dropping out of sight or make them resistant to training efforts.

The third setting is the home. Ideally, a home training team is a component of the medical center, school, or agency-based infant stimulation program. In this circumstance, the curriculum for infant and family can be tailored for suitability to the family's real-life, daily circumstances. Assistance and feedback on follow-through, correction of misunderstood directions, recognition of problems which do not surface in the institutional setting, and more concrete help for families unable to come to the institution on a frequent or regular basis are activities in which a home training team has special advantage. In some communities the home training team may be the entire program, and the home trainer may be a single individual. In other areas the team may consist of a teacher, social worker, and public health nurse who have extensive backup support from their parent organizations.

The point should be emphasized that even with extensive outreach and supportive services, a minority of families with severely handicapped children passively or actively refuse assistance. No single or simple solution exists for these problem families, even under ideal conditions of setting and staffing.

Learning Theory and Curriculum

Even though there is variability in any approach to curriculum or educational methodology, the biologic deficits of the deaf-blind infant dictate that every infant stimulation program focus on program activities that attempt to compensate for this overwhelming deprivation. Program content is very similar in early childhood programs. However, the manner in which these activities are presented varies with the program. In addition, content does not exist in isolation but as part of the program philosophy and model. Three major philosophies or models predominate the early childhood programs used across the country at this time. These philosophies or models include (1) the behavior modification approach; (2) the normal-

developmental approach; and (3) the cognitive developmental approach or the Piagetian model (Anastasiow, 1975). The first and latter models represent extremes along the continuum. The exponents of these models differ philosophically in their perception of the child and how he or she learns.

The dominant view among behavioral psychologists is that all behavior is learned, including affective components such as sociability. While there are substantial differences among leading theoreticians such as Thorndike, Watson, Weiss, Hull, and Skinner, all embrace the Lockian view of the *tabula rasa* of original nature (Hunt, 1969). This belief is based on the assumption that the original nature of mammalian organisms, including man, consists of an abundant repertoire of minute reflexes. The extreme environmentalist view, as espoused by John B. Watson, claims that with control of circumstances a healthy infant from birth through age seven can be made into anything desired. Skinner diverges from the behaviorist view of the human as passive and inactive until compelled to act. He accepts the existence of "operants" and "respondents" as givens. Operant activities are those for which the instigating events in the environment cannot be specified. This is in contrast to "respondents," for which the instigating event can be specified. Although Skinner accepts the existence of operants and respondents, he does not consider that activities have a developmental origin or that they occur as the product of interaction with the environment. In the stimulus-response (S-R) concept, learning reinforcement plays a primary role. Reinforcement is any event following the action of the organism that results in an increase in the readiness of the action or in a modification of the action to occur.

We observe the frequency of a selected response (operant level), then make an event contingent upon it and observe any change in frequency. If there is a change, we classify the event as reinforcing to the organism under the existing circumstances (Skinner, 1953).

Modification of behavior is directly related to motivation. The shaping of behavior that occurs is a result of the rewarding events which follow their occurrence. Therefore, a reward or reinforcer is given to the child when he or she accomplishes the behavior the trainer has set. The primary reinforcer is food, with social rewards considered secondary, although a good behaviorist uses both. The trainer creates an individualized program for the child in which each step in learning a task is broken down

into discrete, sequential lessons. These are taught at a predetermined success rate.

The normal-developmental view views the child as the mediator in the learning process. Age is the variable that structures what the child will be taught. The child is ready to learn an activity at the time when most children can accomplish the skills called for by a particular task. Early childhood education has been influenced a great deal by the work of developmental psychologists Gessell, Shirley, and Hilgard, as well as Lee and Lee, who prepared lists of skills to be accomplished by a certain age (Anastasiow, 1975).

The preschool curriculum of normal-developmental programs consists of those activities and experiences that are considered child growth and development oriented. Lists of age-appropriate skills influence when specific materials will be introduced into the curriculum. The curriculum will also reflect those activities that are considered necessary to prepare the child for entry into a school program, usually the first grade. The children are generally grouped for activities which are teacher-directed. Units of work are developed in which school-related concepts such as colors, directionality, and number concepts are introduced. The child is taught how to behave in school as he or she participates in these tasks. Socioemotional development is also emphasized, but within the context that emotional health influences cognitive development, and therefore, is necessary if the child is to be successful in school.

The cognitive-developmental or Piagetian view views the child as the transactor in the learning process. This view is opposite to and dissonant with that of the behaviorist's position, which views the child as the activator of his or her intelligence. The child moves through a series of age-determined stages that are hierarchically ordered. Piaget feels that the infant has a limited number of highly organized innate behavioral structures that allow him or her to interact with his or her environment from birth. These reflex schemata include (1) sucking; (2) looking; (3) listening; (4) vocalizing; (5) grasping; and (6) the various motor activities of the trunk and limbs (Hunt, 1969).

The infant learns about the world through his or her encounters with the environment. The basic reflex schema undergo progressive adaptations through the processes of "assimilation" and "accommodation." As the infant interacts with the environment, he or she incorporates each encounter through the process of assimilation to form a construction of reality. The process by which the

infant revises his or her construction of reality through assimilation is defined as accommodation. The richness of the infant's experiences and his or her physical actions determine how the child constructs his or her own intelligence. The Piagetian trainer creates an environment rich with objects for the child to act upon. Experiences are arranged sequentially, beginning first with the object, succeeding to observation on how the object is used, and then actual use of the object. Finally, through questions, an analysis is made of the processes involved in the experience. The socioemotional development of the child is also stressed. Piaget and Inhelder (1969) feel that the fundamental need and motivation for all learning is the need to be accepted and loved. Failure is considered fundamental to the learning process as the child learns to accommodate new knowledge through his or her mistakes. Open education—English school variety such as open corridor—is an example of the cognitive developmental approach.

A curriculum represents the translation of a specific educational hypothesis regarding how the child learns into a set of activities which attempt to achieve predetermined goals. In our experience, early educational programs for the deaf-blind or severely multihandicapped child must incorporate elements of each of these child development models. To be effective, reliance on any one approach totally ignores the severity of the handicaps and the wide range of clinical and socioemotional differences among deaf-blind children. An eclectic theoretical approach, based on detailed medical, psychosocial, and educational assessment, provides a child and family profile which must serve as the basis for educational programming for the deaf-blind infant.

The approach most widely used in infant stimulation programs for the deaf-blind is the normal-developmental model. Piagetian programming is lost on the deaf-blind infant and the low functioning deaf-blind child. However, Piaget's hierarchical stages of infant development should be integrated into the theoretical conceptualization related to planning a curriculum. By the same token, a highly structured program of contingency reinforcement often cannot be implemented in a chaotic family circumstance, which many of these children contribute to or inherit. Yet, behavior theory can be integrated successfully into the normal-developmental model and is conceptually valid as a technique for teaching or extinguishing certain behaviors. In addition, some families need the structure of and can implement with zeal a detailed

program of behavior modification. For others the first priority must be given to the emotional damage produced in response to the birth of or the discovery of a severely impaired infant. A Procrustean attitude of making a child fit the program instead of fitting the program to the child and his or her family will have more than its share of failures.

Programs for deaf-blind infants can best be described as structured and containing activities in which the teacher imposes a sequence of planned activities upon the infant. A number of structured preschool programs, primarily for the disadvantaged, have been in operation since the 1960s. While these programs diverge in their views of child development and employ diverse teaching strategies, "the central theme of each has been the imposition of carefully designed sequences of activities upon participating children" (Weikart, 1970). The specific equation for a successful infant stimulation program for the deaf-blind is as yet neither known nor agreed upon. However, an essential part of this equation is that the teaching be systematic and that the curriculum be open-ended and contain a repertoire of activities.

Program Components

A discussion of the components of a full-service early intervention program for deaf-blind children is presented in the following sections.

Parents

Parents of the multihandicapped are in critical need of both counseling and specific skills and techniques to use with their infants. The birth of a handicapped infant precipitates some degree of a family crisis. Guilt plays an important role in the parents' ability to relate positively to their handicapped infant, to their other siblings, and to each other. Support, comfort, and hope are the primary initial needs of the parents. Feelings of inadequacy must be handled directly and indirectly to help parents view themselves as adequate people. Because of the direct role that parental behavior plays in the development of the child, it is important to intervene before the parents' period of mourning turns into abject hopelessness. If this is not accomplished, the infant stimulation program will achieve minimal success.

Recognition of the parent as the infant's primary teacher has encouraged a number of programs for the disadvantaged, developmentally delayed, and the handicapped to focus on early intervention through parent participation. Preven-

tion of cognitive deficits by teaching parents and more effective educational methods has been the thrust of infant education projects developed by Gray and Klaus (1970), Karnes and Teska (1970), Weikart (1970), and Gordon (1973). Intervention is accomplished through parent training during home visitations or home training sessions.

Home visitation and training has a long precedent in the education of blind infants and has been ongoing in Massachusetts, California, New Jersey, and New York. During the 1950s and the 1960s, a number of early intervention programs for deaf infants focused on parent training. The Infant Auditory Training Program sponsored by the New York City Board of Education used a clinical setting to train parents in the use of methods which would facilitate language development. The John Tracy Clinic in Los Angeles introduced a change of format in the 1960s by using the home as the therapeutic milieu in which to teach parents. A simulated home within the clinic was used for this purpose. This approach was used as the model for infant programs developed at the Central Institute for the Deaf in St. Louis, the University of Kansas Medical Center, and the Bill Wilkerson Hearing and Speech Center in Nashville.

The Rubella Project Experimental Preschool for Multihandicapped Children in New York City initiated a program of early intervention through parent training in 1969. The goal of this program is earliest possible detection of deaf-blindness, preferably within the first year of life. Intervention strategies include ongoing diagnosis and evaluation to help the infant develop functional use of both his or her vision and residual hearing. This is accomplished through intensive parent training and counseling. The setting for this program includes both the clinic and the infant's home, with a home training team visiting once a week to ensure carry-over of activities from the hospital to the home.

A number of activities can be used to encourage parent participation in infant stimulation programs. An initial activity is the presentation of the program's rationale which includes a description of the specific objectives and activities planned for the infant. The parents should be told what behavioral changes or developments to expect. This will help them to see the relationship between the activities they observe in the program and the intended goals for their infants. Parents should be told that it is important for them to share information about the infant's behavior in the home so that methods used in the program and

at home are consistent. Parents of handicapped infants need to be informed about the sequence of child development. This information can be exchanged informally or in special workshops.

Parents of handicapped infants often are so discouraged by their infant's failure to respond to them that the program staff must serve as the infant's advocate for a period of time. A method that helps to improve parent-infant interaction consists of actively involving parents in the program as assistant teachers or teacher aides for caring for infants other than their own. This is based on the assumption that the parents' feelings of self-competence are enhanced, their understanding of child development increased, and a repertoire of activities is learned, which the parents can then use with their own infants. Furthermore, having success with another infant encourages the parent to try again with his or her own child. The parents' empathy for one another also increases, and bonds are formed enabling them to offer support to one another.

A group led by a social worker or psychologist also offers emotional support to the parents of deaf-blind infants. Most parents benefit from participation in a forum that allows them to discuss their feelings about their children. They tend to have a more positive attitude about their role as the child's teacher, and their self-esteem increases as a result.

The Staff

Of necessity, staffing patterns vary tremendously from program to program and are dependent upon the financial, human, and technological resources available at any given time. The multihandicapped infant has such diverse needs that no one professional group has the knowledge or the skills to provide all the specific services prescribed. In addition, effective early intervention requires that the staff be able to view the total infant. Some of the staff competencies are no different from those exacted for less handicapped and normal infants. The following are some of the competencies that should be mentioned because they are important and frequently overlooked:

1. Level of knowledge about other professionals, what they can do, and what they cannot do
2. Understanding of the health needs of the deaf-blind infant
3. Understanding of and ability to use evaluation instruments and techniques to obtain the infant's baseline developmental and behavioral level

4. Knowledge of child development stages through the first six years
5. Awareness of the parents' needs and their stage of development in relation to the infant
6. Knowledge of the infant's physical and social environment and the role these will play in carry-over of the program
7. Goals of the curriculum and its relationship to the program philosophy
8. Development of competency in at least one and awareness of all the following areas: language development, gross motor development, visual-motor development, and social-emotional development

An individualized program for each mother-infant dyad must be planned if the infant's educational experience is to be effective. Inservice and teacher training must be an ongoing process so that staff competency continues to grow as the infant develops.

The Infant

The educational needs of the deaf-blind infant are complex. Outwardly, his or her needs approximate those of the normal child: a warm and nurturant relationship with a mother or surrogate in a varied and sensory stimulating environment. However, adaptive substitutions have to be created for the deaf-blind infant to interact effectively with this environment. Tactile and kinesthetic feedback must play the organizational role that vision and hearing usually do in the development of object relationships during the sensorimotor stage. The infant stimulation program must provide an environment that is rich in its variety of tactile objects for the infant to explore. Most programs rely on teacher-made materials to augment the ready-made equipment on the market. Sound and touch toys are especially effective. Toys should be strung across the infant's playpen or crib or presented at midline to facilitate and encourage reaching and grasping. This is an important concept for the parent to carry over into the home. The deaf-blind infant will not be able to coordinate sound with grasping. Nevertheless, audition should be stimulated in the hope that the infant will learn to localize and respond to sound stimuli at a later time. The infant should also be encouraged to track objects visually so that he or she "learns to see" and to reach out and to explore objects spontaneously. Deaf-blind infants benefit from experiences planned to teach them about gravity and their bodies in space. Motor activities which incorporate equipment such as large inflatable

rubber balls and balance boards are used in most infant stimulation programs.

Language development for the deaf-blind infant presents technical as well as managerial problems. Early amplification has been established as an important component of treatment for the deaf infant. Many deaf-blind infants who are unresponsive to ambient sound and test at a profoundly deaf level may, at the age of five, test in the mild to moderate range. For this reason, amplification is generally not used during the first years of life. However, it is worthwhile to explore the use of amplification as soon as hearing loss is confirmed. Low-gain hearing aids should be used initially. Careful observation of the infant's responses and coordination between the audiologist, the intervention team, and the parents are essential. Auditory training should be an integral component of the infant stimulation program. Music and rhythm present the infant with repetitious sounds and the opportunity to introduce gestures, signs, and movements that encourage differentiation of the self. Sign language plus total communication should be introduced during infancy. We have found that projective vocalization increased after the infant used one or two signs appropriately. Behavior modification techniques have proved to be the most effective methods for establishing eye contact with the infant long enough for presentation of the sign. Many parents are resistant initially to the use of sign language. They fear that signing will discourage their child from talking. With support and counseling, parents begin to understand the need for establishing a system of communication between themselves and their infants, and they become quite receptive to learning sign language.

The deaf-blind infant falls behind rapidly in self-care skills. Feeding presents a problem as early as six months of age. From our experiences, we have found that most multihandicapped children have an aversion to textured foods, and if left to themselves, they would drink supplemented milk into adulthood. The introduction of a variety of foods on a chronologic timetable for the normal child precludes this feeding problem, which was faced in programs for the deaf-blind five years ago and to some extent is faced today when an older child is enrolled in a program for the first time. Demanding and expecting independence in eating—finger feeding, holding a glass, and using a spoon at the age-appropriate time for these skills—encourages independence in feeding by the age of three instead of the age of five or seven. Problems encountered are the children's resistance to chewing and cul-

tural factors. Parents' attitudes about what and when their children should be eating are the major determinants of independence in the activity. The time period for bottle feeding varies within cultures. In fact, the discussion of self-care skills must take into account social and cultural attitudes as they relate to infant stimulation programming. This is particularly obvious in the area of self-care skills, but its influence is felt in all other aspects of the program. The success the program has in the infant's acceptance of appliances such as hearing aids and eyeglasses depends directly on the consistent effort the parent expends in accomplishing these goals. The key word here is consistency. The program can teach a child to remove his or her outer clothing and to wash and dry his or her hands, but if the demand between program and home is not consistent, the rate at which the child achieves independence will definitely be reduced. Toilet training cannot be accomplished without the cooperation of the parents. Although the child usually must be ambulatory, the major determinant is the parent's readiness to take on this aspect of training during the preschool period. This program aspect is usually dealt with once the child achieves school age and enters a full-time program.

Accountability

Evaluation has to take place on a number of levels in early intervention: the infant, the parents, and the program. This is a particularly difficult area as intervention programs are difficult to evaluate and progress is often hard to measure. In spite of this, two components of the evaluation process should be included in every infant intervention program for the deaf-blind. Evaluation and reevaluation of the infant must take place on a regular basis. The second component is that activities be well documented. This provides the staff with a feedback loop which indicates whether or not program goals are effective or need to be revised. Both should be done on an individual basis as well as for the program as a whole.

Summary and Conclusions

The need for early detection, intervention, and education has been suggested by research data on deprivation. Children born with the dual sensory handicaps of deafness and blindness are extremely vulnerable to developmental delay and attrition. In addition, research studies have demonstrated the relationships of parent behavior and family environment to the child's development. Infant stimu-

lation programs are expensive and require a great deal of outreach activity, staff energy, and skill. However, saving an infant and family in crisis from further deprivation, dissolution, and disruption more than justifies the cost and the effort expended.

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Home Visitation and Parent Counseling

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The period of time between the last major rubella epidemic (1964-65) and 1970 when nationally-funded services were made available through Regional Deaf-Blind Centers was a time when thousands of families affected by the epidemic were essentially without appropriate service for their deaf-blind children or for themselves.

Evolution of Services for Deaf-Blind

A few centers existed in the United States for training a small percent of the deaf-blind children, but the number of children that could be accommodated by these centers was only a fraction of the children needing these specialized services. At the same time, traveling distances to these few major centers were great for the majority of American families, thereby leaving them without personal contact or effective services. Urban areas maintained diagnostic and child development centers but precise knowledge about deaf-blind children was lacking.

The Need for Home Visits: A Time Without

During that period outreach, home visitation and home training programs as services to rural families with deaf-blind children were virtually nonexistent. A few such programs existed for the blind child and his or her family or for the deaf child and his or her family but the larger number of children exhibiting the characteristics and physical handicaps of the deaf-blind child were caught in a relentless merry-go-round of inappropriate services. Specialized counseling services for parents of deaf-blind children received even less attention during and immediately following this rubella epidemic.

Beginning Home Services for Deaf-Blind Children and Their Parents: A National Project

While national legislation for services to rubella deaf-blind children was being discussed and debated, several educational pilot projects were begun here and there throughout America for these children. Reports of some of these programs were presented at a conference in San Francisco in June, 1969 (Haltén, 1969). Out of the 19 project reports, 14 program representatives reported the inclusion of parents in their programs for deaf-blind children. Twelve of these 14 programs emphasized training parents to become "child trainers." About eight of the reports mentioned efforts to focus on such parent needs as relieving anxiety, enabling parents to better cope with stress, or helping parents work through feelings of guilt, rejection, and depression. Only seven program reports stressed serving parent and child in the home through home visits.

In spite of these small figures, the inclusion of parents in programs and initiating home visitation projects represented a good beginning because most of these pilot educational programs were conducted before federally funded services were implemented nationally in 1970.

Services for Parents at the Regional Level

When the Regional Centers for Services to Deaf-Blind Children implemented programs across the United States in 1970, only one of the ten centers employed a social worker or home counselor at the regional level. Direct services to parents remained at low-priority levels at that time, with highest priorities placed on casefinding and identification of resources for educational services for the deaf-blind children.

During fiscal year 1971-72, two additional centers hired professional personnel for the purpose of beginning counseling services to parents. Since the emphasis was on coordinating casefinding, diagnosis, and evaluation of deaf-blind children, plans to begin state, regional, and national parent organizations were only in the discussion stage. Interest in providing parent counseling and/or home visits was developing but had not yet been implemented regionally.

Four regional centers reported having personnel to coordinate services for parents throughout their regions by 1973. Other regionally coordinated services for parents of deaf-blind children involved regional parent workshops in 1973 and 1974.

Parent Services at the State Level

In a March, 1975, survey of all regional centers, seven reported having begun sponsorship of home training and visitation programs for families of deaf-blind children on the state level between 1970 and 1972. These seven regional centers employed 11 home visitors or itinerant teachers. The background training of these individuals included: teachers of the deaf-blind or multihandicapped child, a speech therapist, social workers, parent educators, a child development specialist, and paraprofessionals with some experience in deaf-blind programs. This does not include the state personnel who were hired to do casefinding throughout the United States. These early itinerant workers covered large geographic areas—often entire states—while serving very isolated families.

A few state deaf-blind educational programs included social workers, psychologists, and parent educators to provide educational and counseling services to the parents of the children in the deaf-blind program. Some parent counseling was done on a referral basis, while other counseling services were extended to parents through group therapy sessions. Very few contacts were made with the parents of deaf-blind children in the state training schools.

Between 1972 and 1974, regional centers increased the number of counselors and home training personnel to more than 55 persons. Also, during this time, six states reportedly conducted intensive workshop and training sessions for social workers and parent counselors. The training sessions represented an attempt to build quality into the state programs and to better prepare those workers to meet the needs of the parents of deaf-blind children in the home setting.

Other states developed plans for providing home visitation through teams of professionals on an itinerant basis during 1972-73. These teams consisted of teachers of deaf-blind persons and social workers who focused on training parents to become child-trainers. The team members also offered counseling services to help parents cope with family conflicts and stresses.

Major Trends of 1975

Fiscal year 1974-75 was a year of greatly increased services to parents of deaf-blind children throughout America. Reports from the regional centers showed that between 150-180 individuals were involved with parent counseling, home training programs, and outreach home visitation projects during that year. Forty-five states were reported as having home counseling services available to the parents of deaf-blind children. Both part-time and full-time counselor services were reported—including those persons who served parents of children in a classroom program and outreach workers who covered entire states. State estimates of parents served ranged from 25 percent to 85 percent of the parents of deaf-blind children across the nation, with the lesser percent being reported by those regions that had just been funded for parent services within the previous two years.

Other trends suggested that over 50 percent of the parents were counseled in individual family sessions. Only five states reported holding group family counseling sessions.

Breakdown of experience and training of those individuals doing parent counseling included social workers, teachers of the deaf-blind, caseworkers from commissions for the blind, counselors for the blind, trained home visitors, teachers of the blind, paraprofessionals with supervision by a teacher, psychologists, general classroom teachers, teachers of the multihandicapped, teachers of the deaf, paraprofessionals with supervision by a social worker, program directors, parent educators with teacher-training that included classwork in counseling skills, speech therapists, itinerant teams, and nurses with training in infant stimulation. Defining the exact roles that each of these individuals assumed in parent counseling and home visitation would be an impossible task to accomplish with any accuracy. General impressions obtained from the regional centers were that a majority of these workers used an education/training oriented approach and spent much of their time training parents to become child trainers.

Many of the respondents from the regional centers indicated that future hiring trends for parent counselors and home visitors were expected to lean more toward trained social workers with some inservice training in working with the deaf-blind. A few respondents stated that several regional and state programs would continue with teachers of the deaf-blind as home visitors but would have the teachers attend intensive conferences on counseling techniques and skills. Others perceived the home visitation team as providing the most comprehensive counseling-training situation for parents. Interviewing and counseling skills and adaptability to unstructured situations such as the home setting were seen as necessary traits for any individual doing parent counseling and home visitation.

Spin-off workers. Project Spin-off was a nationwide program to provide service through trained home visitors to those families not receiving other services for their deaf-blind child. Twelve workers were assigned to various regions. Some concern was expressed about the limited training provided for these workers. Respondents believed that more than three weeks for training and planning would have been helpful for a number of the workers who had never done outreach or home counseling before. However, the majority of regional center reporters perceived the Spin-off project as a major impetus for continuing and expanding services to parents throughout their regions. Other advantages of having Spin-off workers were seen as: identification of additional parental needs; providing data on family environmental and cultural uniqueness; pinpointing gaps in services to parents; providing educational services to the parents within the home setting; increasing new data and psychosocial information on deaf-blind children and their families; obtaining financial assistance for parents; providing liaison between school and parents; assisting some states in making contact with every homebound deaf-blind person in the state; providing effective counseling services to isolated, rural families; and inspiring new parent counseling and home visitation projects. Some respondents believed that a team concept would have been more effective because Spin-off workers frequently seemed to be doing either parent training or parent counseling but not both.

Trends in parent groups. Nineteen states reported that parent groups and parent group organizations on the state level were reported to be on the increase in each region. Continued support of parent-sponsored groups or workshops were

reported by all ten regional centers. Interest ran high in relation to workshops for training parents in leadership skills, legislative procedures, and issues of parents' rights.

Other continuing concerns. Reports from the regional deaf-blind centers included on-going plans for workshops for teachers, stressing parent-teacher relationships and counseling skills and teaching home management; establishing numerous new local community resources for parents; increasing use of mass media to acquaint the public with the problems of the deaf-blind child and his or her family; providing summer educational programs for parents; organizing weekend retreats for parents; creating parent newsletters with question and answer columns written by psychologists and psychiatrists; increasing parent services to reach those isolated families who still do not have appropriate assistance; providing counseling services to parents who have deaf-blind children placed in institutions for the mentally retarded; funding trained baby-sitting services and respite care for parents of deaf-blind children; coordinating parent counseling services on a national basis; coordinating parent services at regional level; adding new itinerant teams to do parent counseling and home visitation on state levels; and beginning studies and research projects on counseling with the siblings of deaf-blind children.

The lists are long and the continuing needs are plentiful, but the accomplishments in the area of parent counseling and home services during the past five years are truly significant.

Tasks of the Home Counselor

Preparation for beginning home visitation programs can be anxiety-provoking to any new home counselor or outreach worker.

Preplanning for the Home Visit

If the counselor or worker accumulates knowledge about the current educational theories and practices for deaf-blind children and their families and takes time to acquire the necessary counseling skills to effectively work with these families, the experience can become an exciting and rewarding one.

Acquire knowledge of the treatment and training of the deaf-blind child. Suggested guidelines for obtaining information and knowledge of this nature include the following:

1. Acquire and read many of the available articles and books on rubella and other handicapping conditions. A greatly increased

number of articles, books, and bibliographies in the area of deaf-blind can be readily obtained through the regional centers for deaf-blind children and through specific deaf-blind projects. The knowledge has become sophisticated and relevant for individuals in centralized programs as well as for those in home training settings.

2. Get out into the field and visit deaf-blind programs. Watch the children and teachers at work and at play. Observe how the teacher presents individualized lesson plans to children of all levels of functioning. Take note of the equipment used and how it is used to enhance residual hearing and vision or to develop fine and gross motor skills. Ask the teacher for suggestions about how it can be adapted or substituted for deaf-blind children in the home.
3. Contact professionals in all disciplines who work with deaf-blind and other handicapped children and question them in depth about testing and training techniques they have found helpful when working with these children. Call and make appointments to meet the pediatrician, nurse, speech therapist, social worker, physical therapist, audiologist, occupational therapist, psychologist, teacher, nutritionist, librarian, program director—all who are actual or possible sources of information for the home counselor. These contacts not only build knowledge for the home counselor but also become appropriate referral resources for the family and the counselor in the future.
4. Visit private and public mental health programs; child development centers; schools with special programs for the deaf, the blind, and the deaf-blind; vocational rehabilitation agencies; and specific foundations and club groups which take interest in handicapped children and families.
5. Attend workshops, conferences, parent group meetings, and community action groups. Take courses in child development, parent counseling, and crisis intervention. Read, observe, consult, be creative. Be your own resource.

Understand family structure, roles, and dynamics.

The home counselor should also have a good understanding of family structure, roles, and dynamics of behavior. When we speak of the structure of a family, we are actually talking about the kinship structure of all the family members. In an

inventory of family membership, we should look at all generations of this family that form the personal resources for this unit. The family structure may include grandparents, uncles, aunts, parents, and children. Some authors speak of framing the family structure in light of where the family resides, including all members of the family that live under the same roof (Pollak, 1960). Other authors believe the nuclear family of father, mother, and their children to be the most frequently observed family structure in today's society as we know it. However, the nuclear family is certainly not the only structure with which we will come in contact. Not only will we work with some extended family situations, but we may be concerned with a number of one-parent families on our outreach list. The home counselor needs to be able to adjust the home program to any family structure. Points to consider in relation to family structure include the following:

1. Those members included in the family structure are already a resource of one kind or another for the family. They may be a helpful or a disruptive resource for the home training program and for the deaf-blind child. The home counselor should evaluate and assess each family member's involvement and devise a plan for how all members can be incorporated into a constructive program of service for the child and the family.
2. Family structure may determine the amount and the intensity of the home counselor's involvement with the family. If the family has multiple warm, supportive resources within its structure, the counselors may not need to see that family as frequently as they see the family with only one parent and few supportive members. When working with a family having limited supportive resources, the home counselor may need to become a part of the support system until other community resources can be brought into direct service. The counselor may also need to reach out into the local community to recruit substitute extended family members such as a grandmother from next door, an uncle from the softball team or the firehouse crew, or a big sister from the high school to provide a family structure where none had existed before. The substitute family can include any community member who is willing to take an active part in providing new strengths and relationships to these sometimes fragmented families.

3. Observe the family structure. Is it a loosely or a tightly knit unit of kinship? Whichever it is, is it working adequately for this family? If it is, leave it as it is. If it is not working well for the parents or for the deaf-blind child, some plan for intervention and increased outside support should be offered.

Early writers commenting on family roles or the function of family members (Zelditch, 1955; Pollak, 1960) have tended to type male and female roles as "instrumental" and "expressive." Zelditch describes the instrumental or male role as: (a) direct responsibility for the solution of family tasks; (b) the authority to make binding managerial decisions; and (c) the primary responsibility for discipline and training of children. The expressive or female role was defined as: (a) responsibility for maintenance of solidarity and management of tensions; and (b) the primary responsibility for care and emotional support of children.

In some countries, the 1960s brought considerable shifting and expansion of the concepts of male-female roles within families. Males and females began to assume roles with which they felt most comfortable or those that were decided upon in mutual agreements. The roles assumed by marriage partners today may be a combination of emotional support, decision-making, leadership in sexual relations, cooperation in division of labor, and sharing the responsibility of discipline and training of children.

Keeping up on the literature on changing roles is a worthwhile goal for the home visitor. Currently many good books and articles clarify the changing male and female roles in American society today. Adult courses in current trends are also a valuable resource for keeping up to date on what is happening. Some contemporary authors (Huber, 1973) are stressing that both men and women now have one main role, that of a human being.

In light of the many role changes some families may be experiencing, one role at least should remain constant for them—the role of the home counselor.

The basic role of home counselors is to work with the families where they are and with the individuals in whatever roles they have assumed or have been assigned until we have established a relationship with them and have assessed the individuals' functioning in those roles. As we assess and evaluate the roles of the family members, we should ask ourselves: (a) Are the family members accepting of and comfortable with their roles? (b)

Are individual roles complementary to other individual roles? (c) Are the family members functioning adequately in their individual roles and in their family roles? Again, we may offer reassurances such as "you are doing a good job; keep it up" if we find that roles are being handled well but should plan intervention, through counseling, if they are not.

If a role disruption occurs because of illness, bereavement, divorce, birth of a handicapped child, periodic crises, or ongoing role conflict, the home counselor should have the skills to help the family work through the disruption. If the home counselor has not been trained in crisis-intervention techniques or in longer term marriage and family counseling, a referral should be made to a trained, licensed, or certified counselor.

In referring to family dynamics, we are really addressing ourselves to interpersonal relationships within the family: how one family member's action (the stimulus) affects the behavior (the response) of another family member. Personality characteristics of family members—whether they are dominant, submissive, competitive, cooperative, defensive, fearful, or aggressive, for example—also influence the interactions of family members. We anticipate that most family relationships will promote growth and maturity for each of its members, but we sometimes meet families in which unhealthy interactions, communication system problems, restrictive family rules, and absence of open linkages to the outside community have reduced the growing edge of one of the individuals or the entire family unit.

Families with deaf-blind children differ very little from any other family except that they may have some unique stresses and pressures because of the deaf-blind child. Once more, we need to assess the family relationships and try to determine where the dysfunction is and how we can help the family work through its stresses. To accomplish this without causing additional trauma, the home counselor must be adept in parent counseling or in interviewing techniques. Intuition is helpful but sometimes faulty. A distinction must be made between the person who is working in the home setting to train the mother to work with her deaf-blind child for educational purposes and that person who is working in the home to help a family work through dysfunctional relationships or emotional problems. Very few people working in the deaf-blind area are trained to do both at this point in time. Home counselors and outreach

workers should be acutely aware of their limitations and training.

Develop interviewing skills and competencies. In preparing for the home encounter, home counselors first need to take a good introspective look at themselves. Self-awareness is an absolutely essential criterion for the person making home visits or doing family counseling. Home counselors need to explore feelings about themselves, feelings about handicapped children, feelings about working in home situations with all socioeconomic groups, and feelings about working with a variety of ethnic groups with different cultural mores. Our feelings about people and circumstances will determine how we relate to or do not relate to those people and circumstances. Other important criteria for the home counselor would include such attributes as self-motivation, responsiveness to needs, ability to roll with the punches, ability to appropriately use supervision and guidance, and the determination to stay with a task until it is completed.

Garrett (1972) states that, although the most skillful interviewing and counseling gives the appearance of being a smooth and spontaneous interchange between the interviewer and the client, the skill revealed is obtained only through careful study and years of practice. Where might the new home counselor start in this whole process?

The following concepts are emphasized by Biestek (1957) and Carkhuff (1972) as necessary components of a good working relationship between the family and the home counselor:

1. Establish a relationship with the individual or the family. All those working with people must learn to reach out and make a meaningful contact with another human being who is hurting. The contact is an emotional interaction between people. If the relationship is a positive one, it leads to a trusting, comfortable, warm, and safe feeling between the two people. If the relationship is a negative one, the feelings evoked can be distrustful, disrespectful, uneasy, and defensive. The people in this relationship are less likely to know what the other is saying or is needing. A good relationship will allow for expressions of anger and hurt in an open and honest way.
2. Allow the individual or the family to use self-determination in decision making. This does not mean that we remove ourselves from the decision-making process but that we facilitate the decision through discussion of all alternatives in an atmosphere of respect

and self-dignity for all the people working together on the decision. Self-determination guarantees the counselor's support without his or her domination.

3. Respect the individuality of the family members. Respect maintains a positive relationship and encourages cooperation and purposeful expression of feelings. Allowing for individuality permits each person to be his or her own unique self.
4. A nonjudgmental attitude on the part of the counselor gives family members the freedom to be themselves without fearing rejection, assuming guilt, or assigning blame. Acceptance of family members is an important element of this open attitude.
5. Genuineness and empathetic understanding by the counselor imply responsiveness to needs and a willingness to share feelings.
6. Confidentiality assures the family that what is revealed will not be shared indiscriminately. Family information should be shared only for professional purposes and only with those persons concerned with the case.

Authors, in an attempt to describe the process and techniques of interviewing, have used terms such as the "skill" and the "art" of looking beyond the "manifested" and the "obvious" behaviors of the client. Garrett (1972) describes interviewing as an art that includes the observation of overt behavior and sees what the behavior says as well as noting what is left unsaid. It involves listening with the third ear, the perceptive formation of leading questions to gain information and to refocus the interview, and the giving of subtle leadership and direction. It involves the ability to be alert to shifts in conversation, association of ideas, recurring themes, inconsistencies and gaps, and the appropriate use of silence. The discussion of such techniques must be abbreviated here, but many theories and numerous methods of application should be studied by the home counselor.

One method of counseling that many social workers and parent counselors have found to be a comfortable and useful approach is the method of supportive interviewing techniques. Selby (1956) suggests two types of conditions in which individuals can benefit most from supportive help: (1) the person with weak ego-structure who cannot tolerate further threat to his or her defensive system; and (2) the person who normally functions quite well but who is reacting to some unusually difficult situation which has temporarily impaired

his or her integrative capacity. Supportive techniques used (*Method and Process in Social Casework*, 1967) include:

1. Providing reassurance. Reassurance becomes a dynamic force when used realistically.

Vignette: Mrs. C. was severely depressed over having given birth to a rubella deaf-blind daughter. Her depression resulted in frequent periods of crying alone in her room for several hours a day. While under a great deal of stress, Mrs. C. was still able to accomplish all of her household tasks and attend church each weekend. The home counselor complimented Mrs. C. on the fact that she was still doing an excellent job of handling her home responsibilities and at the same time maintaining contact with her church. By verbalizing these observations, the home counselor gave Mrs. C. realistic reassurance that she was functioning adequately in these areas of her life and within these roles.

2. Giving information. Information allows for constructive action.

Vignette: Mr. and Mrs. T. are now facing the possibility of placing their deaf-blind son, John, in an institution for the mentally retarded. John is sixteen years old and has been in a specialized home training program for four years. Mr. T. has just suffered a massive heart attack and must stop working for a minimum of six to twelve months. Mrs. T. has had to find a job, since she is now the only healthy adult in the family. Both Mr. and Mrs. T., in the process of making the decision to place John in the State Training School, have been bombarding the home counselor with questions: What is the State School like? Will they take good care of John there? Will he forget how to dress and feed himself? Will they know what he likes to eat or when he needs to go to the bathroom? What will happen to John if his father and I should both die? They had unending questions, unceasing need for information. The home counselor did not have all the answers for Mr. and Mrs. T., but arranged for both parents to visit the State Training School and to meet the personnel who would be working with John. Mr. and Mrs. T. had the opportunity

to obtain the necessary information on which to base their decision for placement. They also had the opportunity to talk with an attorney about Social Security benefits and state provisions for John's care if anything should happen to them at a later date.

3. Encouraging logical discussion. Logical discussion helps the individual make a decision based on the appraisal of alternatives and their anticipated consequences.

Vignette: Mrs. G. was pacing back and forth in her living room while her eleven year old deaf-blind son played on the floor. With a good deal of anger, Mrs. G. expressed her frustration over the lack of communication with her son's teacher about what he was doing at school and how she was expected to follow up on the same program at home. The home counselor helped Mrs. G. define what she perceived to be the specific communication problem, then assisted her in looking at alternative choices available to her to help resolve the problem: (1) call the teacher and ask for suggestions; (2) visit the school and observe specific activities and how they are accomplished with her son; (3) ask the teacher to write out a complete home program; (4) give up and forget about it; (5) write down Mrs. G.'s own activities undertaken with her son, send them to the teacher and ask for comments as to their relevance; and (6) sign up for the John Tracy Clinic Correspondence Course.

At first the home counselor felt that Mrs. G.'s complaints might be inconsequential. However, as the counselor listened and observed the intensity of Mrs. G.'s frustrations, she realized that lack of communication with the teacher was Mrs. G.'s most insistent and urgent problem. Counselor and mother talked over the alternative plans and their consequences. Mrs. G. decided to try alternative plans 1, 2, 3, 5, and 6 for one month and then evaluate which approach had been most helpful as a solution to the communication problem.

4. Demonstrating behavior. Modeling behavior in this context refers to all ways of responding—ideational, emotional, attitudinal, and physical.

Vignette: Mrs. B. felt that she was totally inadequate in relating her concerns about

her deaf-blind child to the doctor. She often stated, "When I arrive at the doctor's office, I have either forgotten what I wanted to ask him about Cindy or the doctor rushes me out of his office in his haste to see another patient and I don't have a chance to ask him the one question I can remember." In this particular instance, the home counselor and Mrs. B. role-played the office visit. The counselor also asked Mrs. B. to write down each question about her child that came to mind during the week. During the next home visit, the counselor and mother reviewed the list of questions together. Again the office visit was role-played with the counselor assisting Mrs. B. in understanding what constituted an appropriate assertive request for information from the doctor. The home counselor used the techniques of modeling behavior and coaching (Rose, 1975).

5. Giving advice and guidance. This technique is used when the individual needs direction or permission to act or because he or she is inhibited by fear, anxiety, or other restricting emotions. It must be used with discretion.

Vignette: Both Mr. and Mrs. W. had experienced severe depression and had become immobilized during the crisis of the death of their deaf-blind son. The home counselor became active in suggesting the steps that Mr. W. should take in making funeral service arrangements. The counselor also advised Mrs. W. to respond to the immediate needs of her other children and assisted her in getting the children bathed and fed. Advice and guidance is not frequently used as a supportive technique because most people take action to make changes when they are self-motivated to do so—not when someone else advises them to do so. Crisis situations could be an exception to this.

6. Setting realistic limits. When the individual is incapable of limiting herself or himself, the counselor may need to do it for him or her until the individual can stabilize or learn to adapt his or her behavior.

Vignette: Paul was deaf-blind, excitable, and physically aggressive at home to the point of tyrannizing his younger brother, Peter. A home visit revealed the intensity of the family problem. Peter was extremely bright and was doted on by his father. Paul

could never win an argument or gain any attention unless he did it through physical violence. During family counseling, the parents were helped to set limits on Paul's aggressive behavior as well as to work more realistically with the rivalry between Paul and his younger brother. With more attention from father for appropriate behavior, Paul became much less interested in acting out his jealousy toward his brother.

7. Ventilating. This allows the individual to release energy bound by unexpressed emotion.

Vignette: When the home counselor arrived at the S. family home, Mr. S. would hurriedly leave the front room. His path, as he travelled through the house, could be followed by Mrs. S. and the counselor as he banged doors, pushed drawers shut with a slam, and stormed out to the garage. After several visits, the counselor followed Mr. S. out to the garage one day. The counselor quietly stated, "The pressures of having a deaf-blind child plus six other children must be terribly great for a man who actually prefers the peace and quiet of working on his cars in the garage." Mr. S. looked at the counselor with intense anger. The counselor's question, "Is there anything I can do to help?" was followed by Mr. S.'s explosive answers, "Yes, someone could tell me what's really wrong with Tom (the deaf-blind child)! Someone can help pay my doctor and hospital bills! I wish some doctor would tell me what those psychological tests mean, and you can tell our neighbors that we don't have something that's catching just because we have a son who is different from their children!" Mr. S. sat down on the bench and the counselor joined him to listen to his expressions of total frustration and pent-up anger. Mr. S. looked tired and exhausted and didn't go back into the house with the counselor for the remainder of the home visit. Mr. S. stayed in the house for all of the follow-up visits, however, and eventually became actively involved in the home training program for his deaf-blind son.

8. Providing direct intervention. This involves the counselor taking action on behalf of the individual or the family.

Vignette: Direct intervention is the counselor's action that changes the reality of the family, parent, or child's situation to enrich the environment or to avoid unnecessary external stress. Probably the most extreme example of this might occur when the counselor, the other team members, and perhaps the family become aware of the fact that a deaf-blind child must be placed outside his home because of neglect, rejection, physical abuse, or the inability of the parents to physically or emotionally provide for the child's continued growth. Other, less extreme examples of direct intervention could include: (1) the counselor taking the active responsibility of providing transportation for the family to go to the diagnostic center instead of asking the family to take total responsibility to find another means of transportation when they do not have a car; or (2) going to the doctor's office with the anxious mother and child and intervening with the doctor—asking him the questions the mother has forgotten or is too fearful to ask.

9. Utilizing habitual patterns of behavior. This involves a deliberate effort to help the individual use old behavior patterns in a new and improved manner. Direction of energy is more constructive so that outward forms of behavior are changed, although the intent of the internal processes are not modified.

Vignette: Mrs. H. spent hours on the telephone, between visits by the home counselor, repeatedly asking her three women friends what she should do to get her deaf-blind daughter to eat or to stop banging her head on the crib rails. The need for reassurance and direction was so great for Mrs. H. that she was gradually experiencing personality disorganization as she continued to receive confusing instructions from friends who had never personally experienced such frustrations. The home counselor took Mrs. H. to the next group meeting for parents of handicapped children. Here, Mrs. H.'s inquiries for directives were responded to by parents who had had similar experiences and had acquired knowledge from professional counselors. Mrs. H.'s pattern of behavior was the same

but now her efforts to find information were constructive.

10. Encouraging confrontation. Pointing out stereotyped or patterned behaviors so that the individual becomes aware of them, can tolerate the awareness, and can improve his or her functioning.

Vignette: Mr. and Mrs. M. are the parents of a deaf-blind child but the primary problem seems to revolve around the fact that Mr. M. refuses to help Mrs. M. with any of the household tasks. Confrontation was used in discussing this with Mrs. M.

"My husband is getting worse. He just will not do anything to help me out at home."

"What did you want him to do that he didn't do?"

"I told him to do the dishes. He said he was tired after working at the store all day and that I made unreasonable demands."

"Then what did you say?"

"I said, 'That's not true. I have to yell at you and demand that you help me out. Why did your mother bring you up to be so lazy?'"

"Did you try anything else to get him to help with the dishes besides reasoning, yelling, demanding, or asking him why his mother let him be lazy?"

"No, I just gave up and did the dishes."

"Reasoning, yelling, asking why he's lazy, and then doing the dishes yourself aren't the same as simply telling him you're exhausted and asking him to do the dishes. Why did you give up?"

"By then, I just wanted him to get out of the house and leave me alone because I was angry. I just told him to go."

"Giving him the choice to go is not the same as insisting that he help you with the dishes. Why did you tell him to go instead of asking him again to help with the dishes?"

"I don't like to be angry so much and it's always such a hassle to stand up for what I feel are my rights. My husband needs some quiet in the evenings, too."

"It sounds like it's easier for you to stand up for someone else's rights than it is for you to stand up for your own. It may not be as important to you to get your husband to do the dishes as to get him to

leave you alone when you have become angry."

"Would you like to talk some more next week about standing up for your own rights?"

"Yes, I would."

Scheduling the Home Visit

In the process of planning for that first home visit, some counselors prefer to look up all old records that might be available on the family members. Other counselors would rather make their own evaluations of the family on the basis of direct observations and communications.

Scheduling a home visit should begin with an initial telephone call or letter to the family. Please don't take them by surprise. This first contact should also clarify the reason for the home visit—that you would like to have a chance to get acquainted with them or that their name has been referred to you by someone whose name they recognize for a special reason. The initial contact should also establish the time of the visit. As counselors, we need to keep the family's schedule in mind and inquire as to times when our visit would be the most convenient for them. Evening appointments could help ensure the presence of the father for the visit. If the father's inclusion in the visit is not possible at first, then the next consideration for time should be for the mother—when she is not busy with meals, dishes, or getting children ready for school or bed. Early morning and late afternoon hours are frequently inconvenient times for a homemaker. To facilitate the decision about the time element, the counselor could suggest two different times to avoid having to work through each hour of the day to find that right time. After the appointment has been established, it is probably a wise procedure to write or phone the family a day or so before the visit to confirm the day and hour of the appointment.

Checking the correct address of the family and the best way to get to their home will save much time later on. If you have a map of the area and take the family's telephone number along with you on the visit, you may save your disposition and your time. Also, give yourself a leeway of 15 or 20 minutes in case unexpected circumstances delay your arrival and disturb the family. If you find that you cannot make the visit as planned, courtesy dictates a telephone call or a letter to explain and to set up a new appointment time. If you arrive at the home and find no one there, leave a note stating that you are sorry to miss the family and

will call again to make another appointment. This could be a very important demonstration to the family that you do care about them and that you are serious about being available to help. Some families need this kind of concrete example to build trust before they will allow you to come into their lives.

Visiting the Family

As you, the home visitor, approach the family's community and neighborhood, try to make mental notes about the local resources you can observe, the kind of neighborhood in which the family lives, the care they take of their lawn, the exterior of the house, and the kind and number of cars. Being a good observer of these elements can help you form a total picture of the family. These observations can also give you an idea of the appropriate manner in which to relate to this family. It may also tell you how the family may relate to you.

The home visitor's mental notes about the family life-style continue as she or he enters the home. Again, the counselor should be aware of the home furnishings and how they are used by the family. For example, is it a warm, homey setting that is totally used by all family members or are certain rooms and pieces of furniture off limits for some members? The feeling about the use of the home can give the counselor some indication of family interactions and rules.

Several questions that counselors are frequently asked by home visitors are: Should we accept anything to eat or drink, and, if the television is on, should we ask the family to turn it off during our visit? Some counselors feel that accepting something to eat or drink depends on the reason the offer was made. If it is a manipulative move, the visitor should probably not become involved in the manipulation. If it is a way of life for the family, go ahead and enjoy the refreshments with the family. Some counselors also feel that the decision about the television should be a family decision since the counselor is a guest in their home. Others feel that the family would respond positively if the home visitor's request for less distraction is stated in an unthreatening manner. For example, he or she could say, "I am sorry, but it is difficult for me to hear what you are saying while the television is on. I want to make sure that I understand what you are telling me. Would you mind turning the television off for awhile?" People usually appreciate hearing that you want to hear and understand and respond by facilitating the process, if possible. With some families, the visit

will need to be scheduled for some time other than during the family's favorite television program or soap opera. Surely the counselor can be flexible about this if it is important to the family. A favorite program can be important to people, even to the home visitor.

One caution about the time period for socialization—if the home counselor spends too much time socializing, the family may think that he or she does not view the problem in the same light as does the family. Timing is of vital concern for the home visitor and for the family.

When the counselor has determined the pertinent topic for discussion, she or he should give full attention to that discussion through direct, purposeful listening. The counselor should accept the attitudes and statements of the family members as fact at this point; don't try to talk them out of their feelings. This could turn into a reason for the family to turn off the counselor. Trust and a good relationship must be established first. For example, if the mother should tell the home visitor that she feels inadequate, the home visitor should not reply that the mother is not inadequate. Such a response can completely close off that communication and at the same time establish the counselor as a person with little ability to get in touch with feelings.

Role of the home counselor during the visit. The role of the counselor during the home visit can include being a catalyst and a dynamic force to keep verbalizations flowing; acting to reduce anxiety, embarrassment, anger and suspicion; and offering support and encouraging all family members to participate in the discussion (Kadushin, 1972). The role of the counselor also includes being an aware observer of family interactions and conflicts and recognizing different levels of motivation for participation in the home program. Helping family members identify the problems to be worked through and assisting the family in separating those problems into workable pieces are also important counseling functions.

Parents of deaf-blind children frequently ask the home counselor to help them set limits for management of behavior and discipline for their child (Kelly, 1966). As the counselor takes on this role, demonstration by working directly with the deaf-blind child is often the most effective approach. If the discipline is focused on the bath, for instance, the home counselor should go to the bathroom with mother and child and give the child a bath together with the mother. Again, if the behavior causing concern with discipline occurs while mother and child are engaged in specific gross

motor activities, the counselor should get down on the floor with mother and child and go through the exercise program with them. This can hold true for any activity. We should work with the mother and child or the family in the setting where the frustrations or troubles occur and demonstrate a consistent approach to the child. We should speak to the child in a natural but firm tone of voice and follow through on the task to its conclusion. Rewarding the child for having completed the task with rewards that are meaningful and effective for this child is a necessary finish. Behavior modification and learning theory concepts can be helpful tools for the home educator or counselor while functioning in the home setting.

Another role of the home counselor is that of a link with the community resources needed by the family. We may help the family compile a personal directory of local assistance including doctors, police, firemen, school programs, parent groups, recreation facilities, local club groups, sources for transportation, church groups, city councils, health and welfare facilities—anything within the community that could add another dimension of living for this family.

Taking a social history of each family member is another function of the home counselor. Developing the psychosocial history involves a process of observing, clarifying, and recording information which can lead to better understanding of the individual or the family. This process assists in identifying areas of dysfunction in the family and helps guide treatment of that dysfunction appropriately. The family history can be obtained over several home visits and serves as baseline data to measure change and growth of family members. The history can also be used to review the goals of the counselor to determine whether they need to be adjusted or changed. Goals and treatment plans are discussed with the family and agreed upon by each person involved in establishing a contract so that working together is purposeful and cooperative whenever possible.

Families have strengths as well as problems. Home counselors take on the role of reinforcing and supporting the strengths that are observed. At the end of the home visit, review what has been discussed during the entire visit and also comment, specifically, on the family strengths. This helps to provide for good closure for the interview and end the visit on a positive note. Positive comments about adequate functioning and strengths can help mobilize these strong points for the family to use until the next visit.

As the home counselor prepares to leave the home, she or he should summarize the major areas of discussion or activities that occurred, reiterate the areas of responsibility agreed upon by all family members, and establish the appointment time for the next home visit.

Recording the Visit

Home visits are really not completed until the records required by the counselor's sponsoring agency are completed and delivered to that agency. Most agencies that use home counselors effectively request a social history on each family visited. Later home contacts are usually reported in summary form at least every six months.

In general a social history includes information about where the family lives; names and dates of birth of each family member; and age, ethnic background, place of birth, occupation, and educational level of each individual member. Information is also gathered regarding medical, social, and psychological aspects of each member of the family unit. This information is especially important in determining the level of function for the deaf-blind child. Assessment and evaluation of the information is the next step in the social history. The last step is setting short- and long-term goals and developing treatment plans for the deaf-blind child and the family. Ongoing reevaluation of these goals that have been set is an essential exercise for the home counselor; nothing remains static when the home visitor is working with people and with human behavior.

Summary

Home visitation, as a mode of intervention, was afforded much attention and importance by the early family and child service agencies in America. When the social work profession began, the home visit was the *modus operandi* of every worker. The status of the outreach technique lost ground for awhile under the impact of psychoanalysis and the focus on the individual. Within the last few years, heavy emphasis is again being placed on home visits as a viable means of providing family and child care. Outreach and home visits are not only used to fill gaps in assistance to families but they are also now being viewed as extremely valuable in obtaining diagnostic information about children and the functioning of the total family. Treatment can be carried out in the home by way of follow-up care or on-the-spot child management coaching, and rural families or families with financial and transportation problems can be reached and have their

concerns attended to on a regular basis by the home visitor.

Home visitation and outreach programs have been an important element of significant deaf-blind projects and effectively used as:

1. An extension of an organized urban deaf-blind program into rural areas where families of these children can receive specialized instruction that is consistent and ongoing in manner.
2. Planned follow-up for diagnosis and evaluation procedures done in major medical and educational centers.
3. A continuing supportive counseling modality to facilitate family unity and cohesiveness and to enhance coping abilities within the family.
4. An invaluable diagnostic and treatment component of the total program for the deaf-blind child when few local services are available.
5. A coaching device or model for discipline and child management of the deaf-blind child and other family members as necessary.
6. A means of meeting the family's educational needs for the deaf-blind child by educational and vocational team members.
7. A means of meeting the family's informational needs regarding use of community resources for additional services.

Other advantages of home visitation programs result from the fact that during a home visit, the counselor is on the family's home ground and the situation can often be less threatening to the family than that of a more formal clinic or office appointment. Also, the counselor is better able to observe the family's customary or natural behavior. Knowledge of family interactions helps us evaluate and assess family strengths and weaknesses and allows us to intervene or to give support for working on these problems in the setting in which the family must operate. Home visits can also give us new insights into hidden agendas or family secrets (e.g., an alcoholic family member or another retarded child) that may be impeding problem-solving.

Home visits often demand intensive involvement by the home visitor in all family experiences. We frequently are asked to share in crises surrounding members other than the deaf-blind child (e.g., funerals, jail detentions, drug problems, unwed pregnant teenagers, rape, child abuse, and suspected incest). These experiences call for maturity, stability, personal strength, and commitment on the part of the home counselor.

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Deaf-Blind Education

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School programs for deaf-blind children have existed in the United States for over a century. However, until recently, there were only a limited number of programs, and the students enrolled in them were usually high functioning and capable of leading a semi-independent life upon graduation. The establishment of Regional Centers for Services to Deaf-Blind Children changed the deaf-blind education picture in a radical manner. Through one act of Congress an entire area of human services moved forward several giant steps.

The types of programs required to meet the needs of the broad range of abilities of the deaf-blind population go far beyond the traditional programs of the past. Parent training and counseling, respite care, infant education, summer programs, every kind of classroom setting imaginable from the most conservative to the most experimental, therapeutic programs, and tutorial-companion arrangements are a few of the programs that go together to provide comprehensive educational services to deaf-blind children. The regional centers have been able to bring together public and private agencies and to utilize the expertise of each group to plan programs, thereby avoiding the duplication of effort and the competition for clients which sometimes result when several groups concentrate on one population. The growth of educational programs actually servicing deaf-blind children has been phenomenal. The regional center concept must be hailed as the success of the seventies.

A brief survey of some of the school programs in operation throughout the nation shows the different directions deaf-blind education has taken in the various regions. The influence of tradition and the philosophies of the regional center staffs may have

been the factors responsible for the divergent patterns.

In the Northeast there has been a marked increase in programs operated by small agencies rather than having all the students attend one or two large programs as in the past. This has led to greater flexibility, a wider variety of programs, and more diversified staffing patterns. However, public school classes for deaf-blind children are virtually nonexistent.

In the Southeast the opposite is true. Many programs are offered in public school classes for deaf-blind children. Some of these handicapped children have been integrated into regular school classes and are either on their own or are with a tutor-companion. Residential programs in the Southeast have been developed in state schools for the retarded, schools for the deaf, and schools for the blind. In the main these programs are sponsored by state agencies rather than by private schools.

In the central regions of the country there is a combination of both public and private programming. A few residential schools offer traditional programs. Numerous attempts have been made to develop strong public day programs or cooperative programs involving both the public and private sectors.

The western sections of the country sponsor many different kinds of programs. The northwestern region has mostly structured programs based on behavior modification techniques, whereas the southwestern region appears to have more humanistic and experiential programs. The Indian population and the large numbers of Spanish-Americans in the western and southwestern sections add to the challenge of providing

appropriate educational opportunities. Teachers soon learn that what worked in Boston may not be the treatment of choice in Los Lunas, New Mexico.

An overview tends to show that as you head west across the country, the regional centers seem to change and become more innovative in their approaches to education. This impression, developed over a period of four years, is a strong one. The East Coast programs, with some notable exceptions, are traditional school programs and appear to be more expensive per student than those in most of the rest of the country. Traditional programs are still in existence on the West Coast, as they are in the Midwest and Southwest, but they break away from tradition and are more experimental than those evident in the East. Perhaps the pioneer spirit still lives in the people who chart new directions through the regional center offices in Denver, Dallas, Sacramento, and Seattle.

Residential Schools

In the beginning there was the residential school. The beginning, of course, was the 1800s, and the residential school has changed a bit since those days. The residential school is still, to many, the only appropriate place to educate deaf-blind children. It still is probably the only appropriate educational placement for some deaf-blind children. Residential schools can guarantee individual attention, consistency, a total educational program, custodial care, good facilities, and a record of proven success with a number of children. School programs in residential schools are expensive to operate because maintenance costs and overhead are added to educational charges such as materials, books, and teachers' salaries. Many private residential schools absorb part of the costs through private contributions or income from investments. State-operated residential schools cannot rely on such funds and find it difficult to carry out the comprehensive programs possible in a private setting. The residential programs for deaf-blind children can point proudly to a number of successes. Except for people like Helen Keller and Robert Smithdas, very few of the deaf-blind graduate from college. But many graduates of residential schools have achieved a large measure of independence and are able to communicate with others in a meaningful fashion. Sometimes it is easy to be critical of residential programs for deaf-blind children, but they do constitute the largest repository of knowledge in existence today about the growth and development of children with visual and auditory deficits.

School Objectives

The objectives of the residential school are the same as those of any educational program, except that they operate within the student's total life experience. Developing each student's full potential applies not only to the classroom but also to the playground and to the cottage or dormitory where the student eats, sleeps, and relates to others. Each objective, whether related to self-help skills, communication, recreation, or vocation, grows broader in scope in a residential setting. If handled correctly the individual student's educational goals become the aim of such people as the teacher, child-care worker, aide to the houseparent, cook, volunteer companion, and of every other member of the staff concerned with the child. Educational objectives are, or should be, the basis for the student's total daily schedule. Living in the residential school is, in effect, like living in a terrarium with the whole environment designed for optimum growth and protected from outside influences, except for those chosen for enrichment.

One of the benefits often enjoyed by the staff in a private residential program is the assistance of consultants who help determine the program objectives. The direct staff members usually know the children's immediate needs, but they are not always aware of the broader educational possibilities that are precipitated by the pressures of society and the economy and that are affected by advances in special education and technology. The state schools and the less well-endowed private schools must rely on the collective knowledge of the few professionals on their staffs, which can be a disadvantage when establishing goals and objectives.

School Facilities

No doubt some private residential schools have excellent facilities that are of great value in the education of certain deaf-blind children. But some private residential schools and most state schools have facilities which are inappropriate settings in which to attempt the education of children with severe sensory deficits. Many such schools were designed for children who have a single impairment, whether visual or auditory, while others were meant to be long-term custodial settings for retarded persons. Some are hospitals rather than schools—others are nothing more than a series of boxlike classrooms attached to or near a dormitory or ward in which the students eat and sleep. A number of schools are so designed to challenge the orientation skills of a person with normal vision and hearing. These schools need someone to lead

the children from activity to activity and offer limited opportunity to develop independent mobility skills.

A vast difference exists in facilities, even in those schools designed specifically for deaf-blind children. In one school the children live in cottages which originally housed blind children but go to class in an esthetically pleasing building—pleasing, that is, if you can see it! In another school the classrooms and living facilities are in the same building, and the child has no need to leave the building during the course of a normal day. This insulation from the outside world detracts from the convenience value of going directly from bed to book. It is really just as unstimulating never to leave the building as it is to be dragged physically from one building to another. Life is just not like that and, as hesitant as one may be in actually defining universal educational goals, the act of living a near normal life is certainly one of them.

In visiting facilities one looks for evidence of the effect that the curriculum or educational objectives has had on the building specifications. But one never really finds it. Either all programs are exactly the same and differ little from traditional school programs, i.e., every school must have classrooms and a gymnasium, or the builders were not informed of differences in curriculum. Whatever the reason, there is no apparent advantage in having an expensive facility rather than an old converted stable or guest house. Few facilities seem to be particularly appropriate to the needs of low-functioning deaf-blind children, and the more elaborate facilities appear to be less than efficient learning environments for children with multiple needs.

One thing seems clear: Educators and administrators faced with tremendous pressures have done their best to convert old buildings, build new ones, and use every inch of space in creative ways. However, they have not been tremendously successful, which can be traced to the fact that the population with which they are dealing is more than atypical—it is unique. The children's deficits and abilities are difficult to assess, and the prescription of suitable educational programs is a task that we are still learning.

School Population

The deaf-blind students who attend residential schools constitute a representative sample of the total deaf-blind population. The higher-functioning child is more likely to be found in a private school rather than in a state hospital, but both types of

facility have their share of these children. Quite naturally, all schools covet the brighter child because he or she shows evidence of progress and communicates naturally with others. The high-functioning child usually possesses normal intelligence and has an auditory-visual impairment. This child may have no other disability. Such children constituted most of the deaf-blind school population prior to the impact of the rubella epidemic.

All programs have large numbers of the middle-level child who needs much individual attention, but who can be expected to achieve a limited degree of independence. The child who functions at this level has some intellectual retardation but is able to develop relationships with others and has a need to communicate. Such a child may eventually function quite well in a sheltered workshop and live in a group home.

The lower-functioning or multihandicapped deaf-blind children will most often be found in state hospital programs or in residential schools operated by social service agencies. These children have such complex needs that a medical as well as an educational program must be carefully planned and carried out if they are to attain any significant progress.

A fact that must be emphasized is that each residential program, no matter how modest, presently serves a wide variety of deaf-blind children. This increases the difficulties encountered in providing an optimum program for each child. If there are 40 children in the school, there should be 40 separate programs with teachers able to work with varying levels of ability and facilities and materials for these teachers to use in many ways.

Some attempts have been made in different parts of the country to place children with similar levels of functioning in the same program. Through the coordinating efforts of the regional centers, this has been accomplished with some degree of success. From an educational and economic standpoint, this type of program might be of great benefit to residential programs.

Methods and Materials

The methods used in residential schools depend upon several things. If the school is a large private or state school for the deaf and/or blind, there will be a conservative or orthodox influence operating throughout the curriculum. The teachers in these schools usually have formal training in special education, and some will be highly skilled professionals who have been prepared to work with children who have numerous sensory deficits. Most

of such schools have teachers of the deaf on their staff, and the influence of deaf education is much in evidence. Until fairly recently the emphasis was on oral communication, but the total communication movement of the past few years has even penetrated the walls of schools in the Northeast. The language curriculum developed at the Rhode Island School for the Deaf (1971) has replaced the more traditional charts and lists in many schools, and transformational grammar has become the passport which separates the sophisticate from the initiate.

Life activities have assumed a new emphasis in private school programs. College or further schooling no longer seems to be the goal for each student, and independent living and vocational skills have taken the lead. Students do grocery shopping for staff members, do faculty laundry, and perform a number of chores which are related to everyday life and personal competence.

In the classrooms teachers use methods and materials designed to remediate perceptual deficits. Most school materials are taken directly from or are adaptations of commercial items produced for students with learning disabilities, or minimal brain dysfunction, or whatever the popular term is in that particular region of the country. Teachers have commented that these materials seem to be quite successful with high-functioning deaf-blind children who manifest signs of central nervous system involvement.

The large state and private programs are able to operate with a pupil-teacher ratio of 2 to 1 or 1 to 1. This makes individual attention and body contact a reality. In addition, there are often ancillary personnel, such as physical therapists, occupational therapists, speech therapists, psychologists, researchers, consulting teachers, consulting physicians, and volunteers, all of whom combine to make the private residential program not only very expensive but also very appealing to parents and other observers. Naturally, all parents would like their child to have these advantages. The aura of all these professionals tends to provide large state and private residential programs with a halo that tends to obscure some of the values to be found in the "poor relation" state or smaller private programs.

State hospital or state-supported residential programs for lower-functioning children are usually just one part of a large complex serving other special needs. Working conditions are far from glamorous, the hours are longer than regular school programs, and the salaries are lower than in large private programs or state schools for the deaf or

blind. In state hospitals there may be no separate teaching area, and the professional staff may be resented because the routine is disrupted, causing more work by turning passive, nonambulatory patients into wandering, curious children. In many cases hyperactive deaf-blind children have been kept in bed through the use of restraints or have spent their days in cages placed over the bed or crib. The deaf-blind educational program takes these children out of bed and teaches them to walk, to eat, and to toilet on schedule, if possible. It also attempts to awaken in them a need to reach out and acknowledge the presence of another person so that some basis for communication can be developed. Many of the children in these programs are physically handicapped from being in bed for years, so physical therapy assumes a paramount role in the educational plan. Because physical therapists are in such short supply in state hospitals, most educational staff members, whether teacher or aide, eventually function in a therapy role. They may consult with a therapist, or they may read and venture out on their own in an attempt to provide some help to the children who have such great need. The ideal hospital school program appears to be therapist oriented—a team composed of speech, physical, and occupational therapists with or without a teacher coordinator but always with several aides to work directly with the children. This interdisciplinary approach pushes back the professional boundaries which serve as obstacles to education and seem to make everyone involved either a teacher-therapist or a therapist-teacher (Mereshon, 1973).

Materials used in these programs include physical therapy items such as weights, pulleys, and bars. Weighted dishes, specially designed cutlery, standing tables, and other devices are used to help the child achieve some small measure of independence. Many items are made by the staff or are contributed by charitable groups. Little money is available to purchase materials, so the creativity of the staff is challenged. The staff may be motivated to experiment and try innovative solutions to old problems.

The two glaring inadequacies in such programs are the lack of experienced personnel with whom to consult and the lack of time to compile data and evaluate results. All energy goes into direct service, and the teacher-pupil ratio can be as high as 5 to 1. Although deaf-blind children are very complex, the teaching staff in public schools often has more than twice the load of the teaching staff in large private or state schools for the deaf or blind.

Summary

Observations of private and state-supported residential programs lead to the conclusion that the well-endowed private schools and the state schools for the deaf-blind appear to have good programs. These programs are somewhat traditional in nature but have adopted newer methods in recent years and seem to be deemphasizing academic subjects as their student population changes.

State hospitals, on the other hand, while understaffed and inadequately supported, seem to have moved away from the teacher-class concept and have embraced the idea of the therapeutic team, with the collective expertise of the group determining the educational plan. Experienced supervisors and more adequate funding would add to the value of such attempts to meet the needs of the lower-functioning deaf-blind child.

The population of residential schools, whether state or private, appears to be fairly homogeneous. Private schools may tend to screen out really low-functioning children, leaving the state hospital programs to cope with those children with the most complex needs.

Education of deaf-blind children in private residential schools must be examined in light of cost as the condition of the economy begins to affect education at all levels. Staff diversification and the elimination of costly overhead items are two ways that state schools have responded to the need to provide less expensive programs. If residential programs are to continue into the twenty-first century, they must move toward cost-and-result accountability.

Day Programs

Day programs for deaf-blind children differ significantly from residential school programs. These differences are far greater than the simple fact that in one type of school the children are there 24 hours a day, while in the other program they come and go from the school on a daily basis. Day programs also differ significantly from each other because of a wide variety of educational approaches, staffing patterns, and physical facilities. In most cases they were initiated in response to intense need, with the encouragement and support of the regional centers and with no established precedents to follow.

Public as well as private day programs exist for deaf-blind children in most areas of the country. The trend is toward the provision of school services in public school buildings, except in New England, where the private school tradition still dominates

in all areas of education. All of the programs, whether private or public, share an air of excitement which is missing in much of education. They have no history, so they dare to try new ways to help deaf-blind children develop and communicate.

Many of the private and state residential programs have a day component. Children from the immediate area are transported to the school either by their parents or a publicly supported bus service. These children attend for the academic day only and do not participate in any nonschool or residential activities. Their in-school program follows the same guidelines established for those students who live at the school. The only way in which they differ from residential students is in the increased amount of parental communication made possible by physical proximity. These children are not considered in the following discussion of day programs.

Private Day School Programs

Most private day school programs are operated by universities or social service agencies such as Easter Seal, United Cerebral Palsy, and associations for deaf or blind persons. They are similar in that they (1) operate on limited budgets with funding through private contributions; (2) do not have to follow state certification regulations for teachers; and (3) have been forced to develop innovative staffing patterns. They are also similar in their ever-present need for money to continue service at a quality level, because it is difficult to recruit professional staff members when salary and job security are not competitive with publicly supported programs. The regional centers, through their financial support of outstanding private day school programs, have done much in assisting private agencies to attract and to keep a competent professional staff.

Philosophy and objectives. Although they are becoming increasingly sophisticated, most private day school programs for deaf-blind children began their operations as glorified day care centers. Their educational experiences, if any, had been with handicapped adults or with children whose handicaps were far less complex than the syndrome known as deaf-blindness. Because their philosophy was one of service, they attempted to do what they could but found that actual developmental needs could be met only if they changed over to a full educational program. Those programs, which began as day respite care, grew into fully functioning schools. They have not, however, lost their medical or therapeutic orientation and have, in most cases,

combined their medicine and education to form a new kind of school which emphasizes diagnosis, prescription, and clinical teaching carried out by a team. The teacher figure has lost its dominance, and the collective knowledge of the team sets objectives and evaluates progress. Careful records are kept, and it is possible to measure movement towards the attainment of long- and short-term objectives.

Many such programs are behaviorally oriented, and the staff receives training in behavior modification techniques. Schedules are maintained, and staff conferences are held to review data. Developmental scales are studied, and charts are kept for each child. Parents are given instructions in procedures to be followed at home and are often required to participate in the school program a set number of hours per week. Such day school programs attack education as a science and attempt to meet each child's needs from this base.

Other private day school programs that operate from a humanistic frame of reference are available. Their philosophy is one of acceptance and hope. They believe that each child has potential. They attempt to surround the children with a warm and beckoning environment, counting on love, attention, and teaching skill to open the child to others and to awaken a need in people to enter the closed world of the deaf-blind.

Both types of programs share the same objectives. They are designed to (1) provide an environment that will move the child from self-stimulation to an interest in the world; (2) help the child develop the skills needed to participate in everyday activities; and (3) encourage the development of each child's potential to be a happy, functioning member of society. In short, the day school takes the "other" child and helps him or her become one of us. All of education seems to have this aim, but deaf-blind education has farther to go to reach the target.

Facilities. Private day school facilities housing programs for deaf-blind children range from the really impressive to the seemingly impossible. Few private day classes are conducted in buildings designed to serve this population. A private home, a remodeled stable, a classroom in a mental health center, a church basement, a converted garage, or any available space has been pressed into service in an effort to respond to the crisis situation resulting from the rubella epidemic. The positive effect of this has been an exploration of new and more creative ways to program education for multihandicapped children without constructing model build-

ings for them. The negative aspect is one common to the whole field of education: the physical facilities rather than the children's needs far too often dictate the education program. The perennial excuse, "We can't do it in this building," is not peculiar to deaf-blind education, but it has been accepted too willingly by some private day schools.

Sufficient funding will never be available to build new and ideal buildings to house all the programs for deaf-blind children. If given all of the unused private school space and all of the abandoned industrial areas in this country, federal funding could be used to encourage architects and interior design specialists to develop innovative and inexpensive ways to convert such facilities into educationally appropriate learning environments for children with multiple special needs. The regional coordinators would certainly be valuable members of any national commission established by the Department of Health, Education, and Welfare to explore such possibilities. All this leads to a most important conclusion: most private and public day school facilities for the deaf-blind are at best inadequate for the type of children using them. Teachers wage unending battles to adapt the school building to allow the children's programs to fit within the four walls. Added to the stress and tension of working with children whose needs require attention is the anxiety of coping with dirt, flaking paint, broken toilets, not enough room, no storage space, poor acoustics, and the greatest problem of all, no money to purchase change of any kind.

The fact that private programs continue at all is a tribute to those who work to repair facilities, paint murals, beg materials from local concerns, and hope for miracles in the future. Much has been done by parents, volunteers from the community, and school staff members to upgrade and maintain facilities used by private day programs for deaf-blind children. The problems will remain, however, so long as money for construction and conversion must be raised privately.

Population. The children who attend private day school programs for deaf-blind children seem to represent a cross section of the deaf-blind population. Some of the differences that do exist are attributable to geography and tradition. In areas where transportation is a difficulty, the more seriously handicapped children tend to be in residential programs. Where the task of getting to class every day is not an issue, the classes represent the full range of deaf-blind educational needs. Rhode Island's Meeting Street School is an exam-

ple of a private day program serving an entire state. Other programs serve only those children in contiguous areas who are able to live at home.

In regions where public school classes are not available, and this is particularly true in the Northeast, private day programs attempt to meet the needs of all deaf-blind children who cannot be admitted to residential schools or state hospitals or whose parents desire to have their child at home rather than separated from the family. Nonambulatory or seriously disabled children are not excluded from most private programs. The one condition for acceptance appears to be the availability of room for one more and the promise of support from the regional center.

Staff, methods, and materials. Facilities and curricula dictate to a certain extent the way in which teachers approach the deaf-blind child in private programs. The major influence, however, is the background of the teacher. Private day school programs tend to be eclectic in their approach because they recruit a staff with varying backgrounds. Traditionally trained teachers seem to be in the minority for many reasons. Private day programs often find it impossible to offer competitive salaries and fringe benefits. These programs demand greater flexibility from the staff, and they often operate year round. The school teacher who thinks in terms of a quiet classroom, a nine-month school year, and collective bargaining has not been attracted to the private programs. Consequently, private day school faculties have a number of members whose background is neither regular education nor special education. Engineers, Peace Corps veterans, nurses, therapists, drop-out students, psychology majors, and many more have contributed to the growth and development of private programs for deaf-blind children.

The methods used in the private day schools have often been trial and error, unorthodox perhaps, but very life-oriented. Not being familiar with the "shalt nots" of blind or deaf education, the private educators have dared to look at each child as one-of-a-kind and have sometimes accomplished wonders by searching out and trying anything that seemed to work. On the other hand many tried and true techniques of special education would have enhanced their efforts and helped them to progress at a faster rate. Personal skills and daily living activities, methods of communicating with blind, deaf, and deaf-blind persons, developmental and adaptive physical education methods, and techniques of working with children having central nervous system involvement

are examples of such special educational areas. These methods and techniques have been used enough to show their value in deaf-blind programs. Noneducators coming into the field can benefit greatly from concentrated inservice training to give them a base from which to work. From observation it appears that the regional centers do attempt to conduct inservice programs to meet the needs of program personnel throughout the region. Regions in which such programs appear most successful are those where the centers have sufficient support staff to provide continuous educational advice. Teachers with little formal training learn to depend on a regular updating of material in their *Teacher's Resource Notebook* (Reilly, 1973) or information on techniques to modify behavior such as contained in the newsletter from the Northwest Regional Center (*Vibrations from the Northwest*, 1973). Workshops and printed materials are made available to private day school staff on the same basis as the publicly supported programs.

Materials used in private day programs differ little from those found in other programs. They are usually adaptations of preschool play equipment, games, and devices designed for perceptually handicapped children and educational materials found in programs for cerebral palsied or orthopedically handicapped students. Elaborate amplification systems for hard of hearing or deaf children are rarely used in private day deaf-blind programs. The expense of such systems precludes their purchase even though the staff is educationally sophisticated enough to see a need for their use with some children. Prebraille and braille materials are not used in these programs, partly because few deaf-blind children appear to be candidates for braille teaching, but mainly because there are few staff members who can prepare children for braille or teach it if the need arises. Specialized educational techniques are not within the realm of most private day programs for deaf-blind children. These programs do, however, meet many of the needs of a population that would have been unserved were it not for the dedicated efforts of the private sector.

Public Day School Programs

Public school programs for children having low-incidence handicaps are not available in all parts of the United States. Prior to the rubella epidemic, they did not even exist in certain areas of the nation. In the New England area, out of necessity, a few public school classes have been established for young deaf children, and the number of public school programs for children

with visual handicaps has increased throughout the country. However, classes designed to meet the needs of severely or profoundly handicapped children are not yet generally accepted as the responsibility of public education.

California has made a strong attempt to provide public school classes for deaf-blind children. Other states provide an isolated class or two for deaf-blind children, but little evidence of a commitment to the right of every child to a public school education in his or her own community exists outside of California. A number of states has good reasons not to provide public school programs, such as the rural character of the state, the small number of identified deaf-blind children, the prior existence of quality private programs, the scarcity of qualified teachers, and the high cost of deaf-blind classes. The fact remains, however, that in most states parents are denied the right to choose a public school program for their deaf-blind child because no such class exists. In a number of states one could argue that the civil rights of deaf-blind children are denied.

Attempts are being made by several of the regional centers to open the public schools to deaf-blind children. As more states respond to legal pressure to provide education to every child regardless of his or her needs, we should see an increase in public school programs for children with severe special needs. For the moment, however, we are waiting for response from the public schools.

The few public school classes that do exist differ greatly. Some are in separate special education centers, while others are in regular school buildings but do not function as part of the school. Some are neighborhood classes, while others draw children from other areas as part of a regional agreement. Most classes operate on a flexible schedule that differs from the schedule of the rest of the school or school system.

In those cases where high-functioning deaf-blind children comprise the class, it may be difficult to find any difference between this group and programs within the system serving deaf or visually handicapped children. The high-functioning child "passes"; she or he can be integrated, needs to communicate, reaches out, and is childlike. The lower-functioning child is the one who presents the public schools with a problem. She or he is not a reader, a subtractor, or a participant. Instead, the schools find a child who needs to learn to dress, to eat, to walk, to toilet, and who needs more than

just a teacher and an aide to accomplish these things.

Some public school systems have responded readily to these needy children, while others have denied such children access to the public schools or have made a room and sympathy available but have kept admission and empathy unavailable. Classes have been and are housed in some public school buildings, but the programs are supported and supervised by either the regional center or a private agency. In these cases, the children never become part of the school in any real sense.

Since public schools do not yet, as a rule, provide an ideal program for the so-called normal child, it appears that the deaf-blind child's rights to a good public school program will be denied for a long time. The need for ancillary personnel, a small pupil-teacher ratio, construction changes in classrooms, an extended or shortened day, and a year-round program are but a few of the unusual demands that deaf-blind classes make upon the public education system. These, coupled with the realization that there is little chance of a deaf-blind child becoming chairman of the board and that many of them will not even learn to read or write, present the average school board with a dilemma. Achievement tests and college board scores are the "stuff" from which public education has been cast, and it will take more than charity and a few concerned parents to reshape the mold.

Public schools do have the one thing that deaf-blind education needs badly and that is steady, secure financial support. Programs which rely on federal grants are shaky at best, and deaf-blind programs need the solid base to be provided by local, guaranteed funding.

Administrative Concerns

There is, to borrow a cliché, no lonelier existence than that of an administrator. This is true at all levels and in all areas of endeavor but, surely, is truest of all when applied to the coordinators of the regional centers and to every administrator of every deaf-blind school program. Think of the person running the deaf-blind program in Charlotte Amalie in the Virgin Islands or attempting to locate deaf-blind children in northern New Mexico. Try imagining what it feels like to be responsible for organizing a new program for deaf-blind children in any state institution for the retarded. A few minutes of such mental exercise and it is easy to understand the fact that administrators of deaf-blind school programs have some very pressing and unique concerns.

Untrained Staff

Without going into a discussion or listing of the university programs that are preparing professional personnel to work with deaf-blind children, it can be said quite simply that in any given year there are very few people who graduate from college and who are trained in deaf-blind education. The numerous specialized techniques, the basic developmental and psychological concepts, and the necessary skills in human dynamics that combine to make a deaf-blind teacher are possessed by an extremely limited number of people. Training teachers of deaf-blind is expensive, arduous, and time consuming. Training has been federally financed for the most part, and the teacher demand will probably always exceed the teacher supply.

The administrator is quite often an untrained person chosen either for courage or past administrative experience in another area of education. In some cases the person in an administrative position did not choose to be in charge but, because of the rapid establishment of deaf-blind programs and the scarcity of people willing or able to lead, was forced into an administrative position either by necessity or default. The task of recruiting trained staff and/or of training inexperienced staff can be overwhelming to someone who is unsure of the exact needs of the children or of the precise techniques which should be part of each teacher's repertoire of skills. The administrator who comes from a regular education background may find it hard to accept the need for so many adults to work with so few children and may also tend to resist the inclusion of therapists into the teaching team.

Staff training has been accomplished to some degree through the efforts of the regional centers. If deaf-blind school programs had to exist without the regional centers, the problems of untrained staff would probably have caused the demise of the programs long ago. The regional center does encourage a chain of hands clasped together throughout the region supporting and helping each program to stand.

Limited Funding

A good, strong educational program for deaf-blind children is an extremely costly enterprise. Few, if any, school programs have the financial support to mount such an effort without outside funding. The administrator has the responsibility of maintaining a quality program while trying to cut costs; of attracting federal monies through innovative programming; and, in the case of private

programs, of organizing fund raising events to supplement the small amounts of federal and state funding available. Deaf-blind education tends to be a hand-to-mouth affair. The administrator cannot sit back and plan for the future because the present level of support is so low that the program operates within a continuous threat of financial crisis. Because minimal funding is secured for only one year at a time, one of the chief administrative concerns will be keeping the program solvent.

Staff Morale

One of the by-products of a teaching career is the sense of accomplishment felt when a student goes on to become a famous doctor, lawyer, or Indian chief. You can revel in the thought that something you may have done gave the chosen one the original impetus needed to start on the path to a brilliant career. Another fringe benefit is watching a bright student achieve and knowing that you are directly responsible for his or her daily progress. Teachers need positive reinforcement, and the successful development of their students is the ideal reward. Increasingly adequate salary schedules, generous vacation schedules, and a realistic work-day add to their sense of well-being. Teaching has become a comfortable profession in many ways, even though its social status has declined over the years.

Unfortunately, these pleasant conditions do not exist for most teachers of deaf-blind children. The pay is lower, the days are longer, the buildings are shabbier, the vacations are shorter, the needs are greater, and the children are slower. Small gains rather than great achievements have been made. Teachers feel that they work endlessly and perform tasks no one else will do. Other educators treat them condescendingly, parents press them for progress they cannot make, and no one shows them any easy way to change the situation. In the end many teachers of deaf-blind children simply despair and move on to another job and a different point of view.

To deny that there is a morale problem among such teachers is to deny reality. The best of programs have staff morale difficulties. Most programs change staff on a never-ending basis. Business enterprises concentrate on staff morale and solve many of their problems through reorganization, incentive pay, vacation trip awards, and public recognition of distinguished service. Educators, somehow, always feel above such things. We foolishly allow many of our best people to work on and on with extremely complex children who

progress so slowly that their teachers receive little if any emotional reward for dedicated and skillful service. No matter how they try, administrators cannot avoid making unreasonable demands on deaf-blind educators. Those in private residential schools are far better off than those in state institutions or day programs supported by private agencies or public funds. Residential programs usually offer many fringe benefits unavailable in other programs. Pleasant surroundings, a number of people engaged in similar pursuits, generous free time, good salaries, and a prestigious status tend to be part of the residential employment package. The opposite is true in most day programs and state schools, particularly those maintained for retarded citizens.

How to combat the low morale caused by poor working conditions and children with tremendous needs is one of the administrator's most complex problems. We have not defeated this morale monster in any of the areas serving deaf-blind children as of this date.

Parent Needs

Working with a deaf-blind child in a school program means becoming involved with the needs and desires of the entire family. The child cannot be divorced from what his or her parents expected him or her to be, what they now despair of his or her becoming, and what the school feels the child has a chance to attain as long as the parents support the school's efforts. School and home must work together, and each must know and understand the other. In most cases the administrator must become the medium through which communication is transmitted.

An administrator must interpret school to parent and parent to school and in the process keep the child and his or her needs before both. School and home are of paramount importance to the child's progress, but the administrator has the unhappy task of weighing both against what he or she perceives to be the needs of the children.

Children's Needs

An administrator in a deaf-blind school program may or may not be close to the children, depending upon the size of the school. In small schools the administrator may work directly with the children in addition to supervising the program; while in larger schools, the administrator may operate several levels away from the actual class or school program. The small school leader has a much easier time maintaining a closeness and a real

awareness of the children's needs. However, the frustration level of the small school administrator may be very high because of the inability to meet the needs of each child. In larger schools it is easier to become involved in administrative maneuvers designed to make things simpler, because the children's pressing problems are filtered through others and tend to be seen as words, not problems. Administrative convenience can too easily become the motivation for changes or nonchanges, depending on the director's own personal biases.

The concern, then, is twofold: one, that of helping personnel in the small school to obtain some objectivity, to use administrative techniques to preserve their sanity, and to help them make progress toward meeting children's needs through a planned program rather than as a response to crisis; and, two, to bring administrators of large programs closer to the children they profess to serve so that the reasons for administrative actions flow from the goals set by the teachers in response to the needs of their students.

As the program continues the administrator needs to develop a process whereby he or she operates as a focal point in a cycle composed of teachers and parents, with the children at the point of origin. In this way the administrator will always operate out of knowledge and concern for the needs of the children (Figure 1).

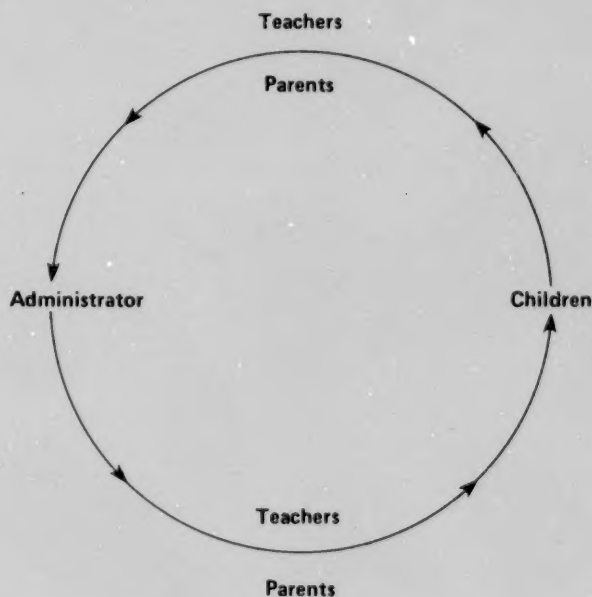


Fig. 1. Cycle of contact

Curriculum

Any discussion of school programs which ignores the issue of curriculum development and/or choice would be incomplete. Although educators are not in agreement about the approach to or the definition of curriculum, much time and effort have been expended in researching, developing, and using various curricula.

Some doubt exists as to whether what purports to be a curriculum may not actually be a statement or description of a methodology.

Nevertheless, a large number of commercial as well as unpublished curriculum guides are available to the special educator. Some of these guides are designed specifically for use with deaf-blind children, while others are adaptable or have been revised to meet the needs of deaf-blind programs.

Some examples of these are the Perkins curriculum, the Teaching Research curriculum, the Meeting Street School curriculum, and various training programs in use at state schools such as the Pinecrest State School in Louisiana and the Lincoln State School in Illinois. Of these, only Teaching Research has a commercially available curriculum that is designed for use in multihandicapped education. All of these curricula are working models which are subject to constant revision. Without participating in their use, it would be difficult to evaluate their value or relevance. They are successful to the extent that the staff is comfortable with them and the needs of deaf-blind children are met.

Without attempting to compare or comment, it may be helpful for the reader to examine the examples from two of these curriculum guides on pages 194 and 195.

These are fairly typical examples of the curricular material in use in many deaf-blind school programs. Some are behavioral in base and technique, while others tend to have humanistic origins. All appear to be designed to provide step-by-step instructions which may be followed by relatively inexperienced personnel. This may be both their strength and their weakness. However they are judged, they represent the state of the art.

Implications for the Future

Some of the current issues which seem to demand comment are as follows:

1. The growth and development of the regional centers and their great value head the list. No other area of education has such a nationwide

network, especially one that includes programs in the Caribbean and the Pacific as well as mainland activities. Ideas have spread, people have come to depend upon others thousands of miles away, and a potential has been developed for an educational research and intervention program without parallel.

2. Federal funding of many direct service programs dealing with multihandicapped children has set a precedent for similar support for other severely handicapped children not being served.
3. Relatively inexperienced professionals have been appointed to powerful administrative school positions and appear to have been highly successful in meeting the demands of the role.
4. The expense of operating low ratio teacher-pupil programs is so tremendous that other staffing patterns utilizing nonprofessionals must be designed if deaf-blind education is to continue and flourish.
5. Intensive inservice experiences seem to be at least as valuable as prejob education in colleges and universities.
6. School programs have not used any meaningful or sophisticated research and evaluation techniques to demonstrate that their efforts have actually accomplished anything.

Many other significant points concerning school programs are in evidence, but those above seem to be of great importance as we consider the future. As in all disciplines, varying points of view exist, depending upon one's educational philosophy and frame of reference. Some deaf-blind educators still are quite parochial, while others are open to all ideas and believe in the sharing of many ideas. Regardless of one's bent, there are advantages to discussion and debate among professionals.

Diversified Staffing

One issue which lends itself readily to debate is diversified staffing. Although there is agreement as to the expense of deaf-blind classes, there is disagreement as to the solution to this problem. Diversified staffing seems to offer programs an opportunity to obtain enough personnel without having to pay each participating adult a teacher's salary scale. Certainly there are many daily school activities which do not require a master's degree in special education. In areas of the country where educators with degrees are scarce, necessity created staff diversification and it has worked. In metropo-

litan eastern schools, however, even assistant teachers tend to have four years of college, which is fine in areas where such people are in ample supply, but it is an inordinate luxury in most of the country. If many programs adopt such traditional standards, they will soon price themselves out of existence, all the while bemoaning the shortage of qualified personnel.

Social service agencies are in the vanguard when it comes to creative staff patterns. Poverty has taught them to train and use willing hands and open hearts, and they operate economically and fairly efficiently. Instead of several physical therapists, the bus driver is taught to carry out adaptive exercises between field trips. Volunteers teach daily living skills, while high school students earn credits for learning sign language and fingerspelling so that they can work as unpaid aides in programs for the deaf-blind. Students from university programs in special education, business administration, and occupational therapy spend entire semesters as unpaid staff members, learning as they work, benefiting themselves and the school program.

One master teacher planning for a team of semiprofessionals can efficiently handle a fairly large group of deaf-blind children. The career ladder must become a reality if all deaf-blind children are to have their needs met. We cannot afford to finance the long education of a graduate student who will work with only two children. The days of such indulgence are behind us. Each program should be assisted to design a staffing pattern utilizing volunteers, aides, semiprofessionals, teachers, and master teachers. The goal actually is the involvement of more people in the education of more deaf-blind children at less cost.

Total Life Education

The trend in most deaf-blind programs is to look outward and to use the community as a part of the curriculum. Since few deaf-blind children in programs today will attend college, their education must be for life in the everyday world to the extent possible for each individual. The emphasis is, and will become increasingly more so, on survival techniques and on methods of coping.

The deaf-blind child needs a practical education. He or she learns to dress, to eat, and to get around in his or her environment. Sheltered living situations must be set up for the deaf-blind person's future, and these people must be taught how to manage in such environments. Through an education for life the child must be shown how to enjoy himself, to have warm and supportive relationships

with others, and to deal with his or her own frustrations. Those who will return to or remain in state hospitals or schools for the retarded must learn how to adapt and how to find some pleasure in such a limited and confined setting.

Total life education looks at the deaf-blind person as a social being with needs other than academic or biological. To the extent that school programs meet these other needs, often unidentified, they will be successful in the future.

Regional Planning

Some regional centers have been more successful than others in organizing their resources to plan for the region. The task of convincing independent agencies that they should sublimate their private interests to serve the public good is never an easy one. Competition for certain types of children is as common among school programs for the deaf-blind as it is with any other kind of handicap.

Where programs have not existed in the past, it has been easier to set priorities and to develop programs serving different levels. Where traditional programs have operated for many years, it is difficult to make changes. In some geographical areas of the country, distance and natural obstacles work against efficient regional planning. Several states do not readily abrogate their rights, although this does seem to occur without rancor west of the Rockies.

Carefully considered regional planning can lead to better programs for children. The needless duplication of residential programs for small numbers of children, the isolation of deaf-blind children from normal children, the creation of competing social service agencies, and the organization of research programs too small to be relevant are a few of the many mistakes that could be avoided if all programs for the deaf-blind were involved in a planning effort coordinated by their appropriate regional center.

Planning for a reorganization of school programs should be a prerequisite for federal funding. The federal Bureau of Education for the Handicapped should have sufficient qualified staff to guide and assist the several regions as they move toward efficient utilization of their numerous resources.

Communication Among Professionals

The education of deaf-blind children is a highly specialized endeavor. At any one time the number of university students preparing for this field is small. The professionals working with deaf-blind children add up to a small number as well. It would

seem relatively simple to develop a communication network involving all of these people. Everyone working or planning to work in school programs for deaf-blind children should be aware of what everyone else is thinking or doing as it relates to the children's education.

As it is now most regional personnel know a little bit about their own region, and the center staff has access to material about other regions. We need to develop some way to exchange professionals between regions, between programs within regions, and between university faculty and program and regional center staffs. Visiting professorships, exchange teachers, retreats for selected personnel throughout the nation, closed circuit television programs, conference calls, or anything that brings professionals into close contact with each other to share, to argue, to propose, to agree, to get to know and respect each other, are immediate necessities. People talking to each other leads to change, to growth, and to reappraisal. Communication among professionals always means death to the status quo. Deaf-blind education is an exciting and dynamic discipline with a long way to go. It requires the efforts of many to move it ahead.

The whole field of deaf-blind education has been taking giant steps in the past few years. So much has been done in such a short time and done so well. In every program intense efforts have been made to offer each deaf-blind child the best educational opportunity possible.

Two problems remain: (1) there are still children who have not been enrolled in a school program; and (2) there will never be enough teachers. However, any group of professionals who could

accomplish so much between 1968 and the present should be able to solve these problems.

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Teaching Research Curriculum, 1973

Dressing

Tie Shoe Laces:

Steps

17. Child ties shoes independently.
16. Child pulls laces snug on shoes.
15. Child grasps right lace with right thumb and forefinger and left lace with left thumb and forefinger.
14. Child places both laces to one side of shoe.
13. Child crosses right lace over left lace.
12. Child grasps right lace and brings it under and through the left lace.
11. Child grasps ends of laces.
10. Child pulls ends taut.
9. Child grasps left lace end with left thumb and forefinger.
8. Child brings lace end to middle of lace, forming a loop.
7. Child grasps loop with left thumb and forefinger.
6. Child grasps right lace with right thumb and forefinger.

5. Child brings right lace all the way around left loop.
4. Child pushes right lace through and under left lace loop with right finger.
3. Child releases left loop and grasps new loop that has been pushed through.
2. With other hand, child grasps other loop.
1. Child pulls loops taut.

Snap:

Steps

4. Child snaps a snap.
3. Child makes small fold in underneath fabric close to snap with thumb underneath snap and index finger on top, close to snap. Grasps top snap and snaps together.
2. Child grasps top snap with thumb over snap and forefinger holding cloth, places on bottom snap, and pushes.
1. Child places top snap over bottom snap and pushes.

Curriculum Guide
(Lincoln State School, 1973)

Area	Objectives	Apparatus/location	Examples of methods/procedures
Motor	1. Movement of arms and legs 2. Locomotion activities of rolling, crawling, scooting, walking, and climbing steps 3. Propulsion activities such as pushing, pulling, throwing, and hitting 4. Holding includes ability to grasp and hold object 5. Balance 6. Strength	In large motor training area: - vestibular board - mats - ladder - roll barrel - practice steps - slide - trampoline - scoot boards - tricycles - wagon - rocking boat - parallel bars - walking board - walkers - bobath ball At tables with chairs using many small objects such as: - blocks - balls - clothespins - nails - styrofoam - spoons - rubber bands - wooden nuts and bolts	1. Manipulation of limbs on a regular basis to prevent stiffness. 2. Use of muscle relaxation exercises to increase range of limb motion. 3. Use of ice therapy. 4. Use of coactive movements with trainer. Trainer's guidance is phased out, and student becomes able to function independently. 5. Development of independent ambulation. Student uses a stick for support, then a coat hanger, and then a piece of cloth in both hands, all with trainer's guidance. Student holds on to a piece of material alone and, finally, walks independently. 6. Coactive rolling a ball. Trainer's assistance is phased out, and student stands and throws a ball. 7. Transferring objects from one bucket to another, pulling nails from styrofoam, clipping clothespins to clothesline, stretching rubber bands over nails in board, and screwing wooden nuts onto bolts. 8. Walking between rungs of ladder, sliding down slides, balancing on beam, using trampoline, somersaulting, carrying trays back at meals, riding tricycles, using vestibular and rocking boards, working on parallel bars, and using walkers.

Prevocational Services for Deaf-Blind Persons: The State of a Pointillistic Art

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Several trends need to be monitored to ascertain the direction and effectiveness of service delivery to adolescent and adult deaf-blind persons. The comprehensive special education acts have established requirements for special educational service, regardless of the degree of impairment of the student. Part 625 of the Education of the Handicapped Act called for postsecondary training programs for persons with disabling conditions. This federal directive will have impact on existing state policies and procedures and may serve as a base for further program services. Recent federal court cases have directed services into a more positive vector to include all children in educational services. The court cases may serve as precedents for developing program services for youth and adults (Laski, 1974). Current programs definitely provide the vehicle for further services, specifically as related to the issue of prevocational services (i.e., transitional services from educational settings to adult living situations) as related to the current litigation and legislation. These may serve as the pivot for further expansion of services.

A second area of change is attitudinal and seems to be reflected in the movements behind the litigation and legislation. In the past, if a person could be labeled educable or trainable, the problem was somehow solved. This often led to exclusion rather than inclusion of clients/students. The attitudinal change is one of a more mature understanding that all children need services and that these services may be included in any program through a variety of approaches. This represents progress in the attitudes of professionals and eventually in approaches to service delivery. Even without litigation and legislation, professional personnel considered the viewing of a deaf-blind person, or any person for that matter, in terms of labels of

functioning as irrelevant. Any living organism is going to change. Denying this either by excluding the child from a program or by limiting the services available to the child simply prolongs the rehabilitation process and develops neither the coping skills needed by deaf-blind persons nor the reality skills needed by professionals to provide appropriate services. This same principle applies to those providing vocational rehabilitation services. Denying the difficult-to-serve client, ignoring the cases which cannot meet closure with minimal training, and failing to understand the true needs of multihandicapped persons by vocational rehabilitation agencies delay the development of services to clients.

The emphasis in the term "prevocational," as used in this paper, is on the transition from one setting to another. Particular responsibility is placed on the prevocational deaf-blind program preparing the deaf-blind child for entrance into a range of adult services, rather than in providing personal adjustment training to prepare the deaf-blind person for specific work training.

A behavioral model of rehabilitation has been proposed (Hammer, 1973). This approach was an attempt to shift the emphasis of adult services in vocational rehabilitation from the criteria for potential for gainful occupation to one of monitoring the client's movement from levels of dependent function to levels of independent function. This option has not been implemented. However, major gains seem to have been made in increasing awareness of the future needs of deaf-blind persons as these needs are identified by vocational rehabilitation services (English, 1974).

Thus, with these trends in mind, the South Central Regional Center for Services to Deaf-Blind Children at the Callier Center for Communication

Disorders proposed to the Bureau of Education for the Handicapped a cooperative study to assess the delivery, and the potential for delivery, of prevocational services throughout the nation. This study was approved and implemented during academic year 1973-74 by all the other regional centers. The goals of this undertaking were to do the following:

1. Define the needs of deaf-blind children for vocational rehabilitation services.
2. Establish nominal groups of clients, agency personnel, and providers of services to identify their concerns, priorities, and responsibilities.
3. Develop systematic approaches to assess the vocational potential of deaf-blind clients, and relate this to job placement and the employment market.
4. Develop prevocational assessment approaches which relate to program strategies for young deaf-blind clients.
5. Follow up on deaf-blind clients who have participated in vocational rehabilitation services for assessment of program goals and objectives, methods of training, and work adjustment achievement.
6. Develop staff training programs to ensure quality services for deaf-blind clients through systematic presentation of methods and resources to those working with the deaf-blind population.
7. Provide services on a pilot basis for a limited number of clients during the 1973-74 school year.

Each regional center was contacted and asked to review the above goals. From the list of goals, specific activities which could be undertaken in each region were identified.

Responses from the regional centers varied, but in view of the broad picture of current efforts, activities seemed to emerge across the nation to develop services for deaf-blind persons. A total picture of available activities emerges when they are viewed at a distance. This pointillistic approach permits the question to be raised: How can current isolated program efforts be coordinated to culminate in appropriate adult services to deaf-blind persons?

Review of Regional Center Activities

A review of the activities of the regional centers for services to deaf-blind persons may present a clearer picture of the current programs in prevocational services.

Southwest Regional Center Activities

Three projects resulted from a planning meeting called by the staff of the Southwest Regional Center for Deaf-Blind Children. In a project at San Francisco State University, personnel tried to define the training needs of persons working with adolescents and youths who were deaf-blind. They listed five goals for clients:

1. Freedom of choice—to expose clients to a range of activities designed to develop and improve skills for independent living, supervised living, work orientation, or adult living
2. Self-respect—to provide socialization opportunities through models of adult behavior to develop positive self-concepts in each client
3. Self-sufficiency—to move from a level of dependence to some level of independent living through experiences in such activities as money management, cooking, shopping, and self-care
4. Socialization—to develop peer relationships and interpersonal relations
5. Travel and mobility—to provide opportunities for orientation and travel experiences, use of transportation facilities, and problem solving

In cooperation with the California School for the Blind, a pilot study was conducted by staff of the personnel preparation program at San Francisco State University to assess those skills identified above in deaf-blind clients. From this study, a series of competencies was identified. The following competencies were proposed as training modules for staff: (1) Demonstrate knowledge of categories of children to be served in a prevocational program; (2) Demonstrate knowledge of various levels and categories of skills to be taught to the children; (3) Demonstrate knowledge of various forms of communication used by deaf-blind persons in vocational settings; (4) Demonstrate ability to organize, plan for, and teach a time unit to deaf-blind children; (5) Demonstrate ability to organize, plan for, and teach a money management unit to deaf-blind children; (6) Demonstrate ability to organize, plan for, and teach a shopping unit to deaf-blind children; (7) Demonstrate ability to organize, plan for, and teach a cooking unit to deaf-blind children; (8) Demonstrate knowledge of local resources for prevocational and career development training for the handicapped.

The competencies are indicators to be used in developing training sequences for personnel, teaching-learning experiences necessary to meet the

expected outcome of each competency, and evaluation procedures to be used by the teacher candidates as well as the instructor of the teaching personnel. Currently, personnel in training are receiving opportunities to implement this competency-based approach in working with deaf-blind persons.

The John Tracy Clinic in Los Angeles conducted a project utilizing experts in the field of service delivery to plan for the future needs of deaf-blind children. Selected individuals submitted papers prior to the conference, "1980 Is Now," to facilitate discussion of the entire range of future needs. The following conclusions were reported (Sherrick, 1974):

1. The planning efforts of all agencies of the federal, state, and local governments, as they relate to the problems of services to the deaf-blind, must be concerted to avoid duplication and inefficiency, and must be initiated within a very short time if realistic goals for this maturing population are to be met by 1980.
2. The more accurate definitions for the terms "deaf-blind" and "rubella child," among others, await the compilation and processing of data on numbers of such multihandicapped individuals as well as on evaluative procedures and diagnostic results.
3. The stress placed by various authorities on need for a continuum of services from childhood through adolescence and adulthood was reinforced by the conference. In the repeating of this call for uninterrupted support of development of the handicapped person, the importance of close interagency cooperation (e.g., between the Bureau of Education for the Handicapped and social and rehabilitation services) cannot be overemphasized.
4. Although a number of current projected programs for training personnel involved in services to the handicapped are on record, it is not clear that the distribution of skills and levels of competence match the requirements. A working conference with a specific agenda and papers should be convened as soon as possible to identify and formulate those areas of competence needed for dealing with the handicapped population of the 1980s, ranging from paraprofessional personnel through highly trained specialists.
5. Efforts should be made to fund the development of a spectrum of model living and working styles for the deaf-blind, ranging

from sheltered satellite homes to sheltered employment sites to foster homes in normal communities. The impact of the model programs on surrounding communities should be gauged, if possible. A major part of such programs must be the careful evaluation of the social, intellectual, and vocational progress and achievement of the individual, as well as the evaluation and documentation of the program as a whole.

A third project of the Southwest Regional Center for Deaf-Blind Children was the development of a precareer curriculum guide for deaf-blind (Carr, Zemalis, and Evans, 1974). This cooperative project of the Home for Guiding Hands at Lakeside, the California School for the Blind, Berkeley, and the Southwest Regional Center for Deaf-Blind Children, Sacramento, was conducted by Evelyn Greenleaf and concentrated on expanding the competencies of deaf-blind children in the areas of self-sufficiency, partial sufficiency (employable but needing supplementary financial or living arrangement support), sheltered workshop (dependent living arrangement), and dependent living in the home (help in home, self-care, recreation, and subsistence on Aid to the Disabled). A retrospective study was conducted to identify current living/work status of students who had received prevocational services. These students would be considered high functioning in that they had been able to participate in the program at the California School for the Blind and had been able to acquire some academic, language, and self-care competencies. Of the 37 questionnaires sent out, 18 were returned by May 27, 1974. The following is a compilation of the responses:

Two-thirds (12) of the students are living at home, two are in foster homes, one is in a residential institution, and one is living independently. Of those parents responding to the question about wages earned by the child, four reported wages over \$100 a month, three over \$200, and one between \$300 and \$500.

One-third (5) of the students are currently employed or had held jobs at one time. Ten were unable to obtain employment.

Of the remainder of the families, five depended on Social Security and Aid to the Disabled, five on State Aid to the Blind, three depended upon family support, and one received help from the Veteran's Administration.

For job preparation, the areas of study in school were diverse. Some had received educa-

tion in a program for the deaf-blind or hearing impaired; while others had courses of study in history, English, the arts, and special training in veterinary sciences (Carr, Zemalis, and Evans, 1974).

A second step of the study was to ask 36 professionals working with deaf-blind persons to project for deaf-blind children the setting which would be most needed when they became twenty-one years of age. Figure 1 reports the projections of placement as viewed by these professionals.

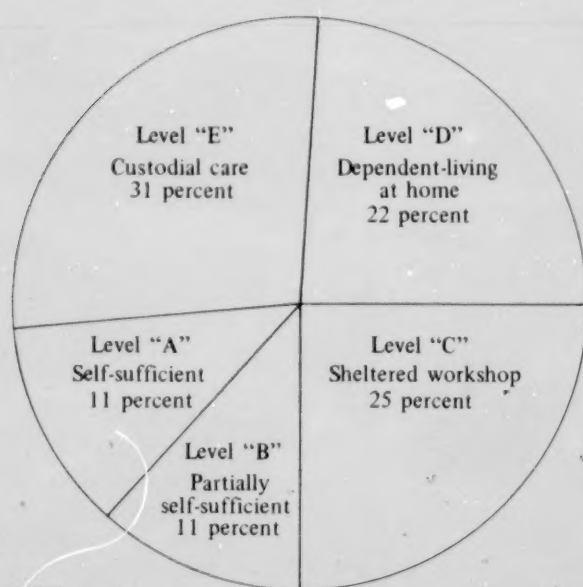


Fig. 1. Professional projection of thirty-six deaf-blind youths

From the data included in the original study (Carr, Zemalis, and Evans, 1974), a precareer curriculum was outlined in the following areas: motor skills, daily living skills, activities of daily living for adults, and a series of manipulative skills oriented toward specific work. The authors cautioned against using the guide for specific trade preparation but encouraged using it to assist deaf-blind persons to participate in gainful activities as part of their lifetime endeavors.

Part three of the study included curricular activities concerned with presheltered workshop manipulative activities. These were designed to give classroom teachers a guide in developing simulated work experiences for deaf-blind youth. The guide also included a continuum of manipulative development, beginning with basic activities and proceeding to post-training placement. A list of agencies for possible job training placement was

included in the appendix of the study. This initial study would serve as a basis for the development of an inventory of existing and potential resources to serve this population.

Mountain Plains Regional Center Activities

In 1974 a study was undertaken by the Mountain Plains Regional Center in Denver to plan for prevocational and vocational services for deaf-blind children and youth. This project included the following as major goals: (1) Identify those agencies that may assist with planning, developing, and conducting vocational programs for deaf-blind youth in the region; (2) Identify those services that each agency may or can provide; (3) Identify the overall vocational educational needs of deaf-blind children and youth in the region; (4) Provide inservice training to representatives of agencies identified through the initial survey; (5) Supervise program development in the region; and (6) Employ appropriate staff to initiate pilot programs in the region.

Through a series of regional and statewide workshops, a basis for providing inservice training to vocational rehabilitation and career education personnel was established. The purposes of this effort were to create an awareness of the potential of deaf-blind persons to benefit from prevocational services, to underscore the need for programs to plan for the future, to identify the types of services children would need in the future, and to detail a model prevocational program which might be utilized in each state. Agencies that were currently providing services to adolescent or adult deaf-blind persons were identified. This activity pinpointed minimal levels of function for agency services. It was therefore possible to design curricula as an integral part of each child's educational plan, which led to appropriate services in the prevocational and vocational area. One paper (Stark, 1974) addressed the need for transdisciplinary approaches to evaluation and for inclusion of families as part of the rehabilitation process. Another paper addressed the issue of evaluation of services at the programmatic level so that services might be applied in planning services and providing appropriate opportunities for each deaf-blind child to meet future lifetime functions (Brooks, 1974).

The outcome of that effort has been the establishment of a dialogue among those providing services to deaf-blind persons so that common concerns may be addressed and pilot programs for deaf-blind youth and adolescents may be established.

New England Regional Center Activities

The Oak Hill School, in cooperation with the Connecticut Institute for the Blind, conducted a study entitled "A Planning/Operational Program in Prevocational Education for Deaf-Blind Children" (LaPorte, 1974). The objectives of this project included activities in self-care skills, manipulative skills, social relationships, recreational activities, experiences with objects and manipulation of the environment, and specific work tasks. Assessment of each deaf-blind child's level of performance in prevocational and personal management skills was undertaken. These objectives were tested in a summer program and a prevocational program.

The Perkins School for the Blind developed a pilot community residence training program for young adults who were deaf and blind, integrated with blind youth in a home training setting. The fundamental concept was that the training milieu would be closely related to the living quarters. From this, the seven deaf-blind youths would become responsible for continuing their training program but would reside in an independent setting where they were also responsible for home-making and management. The curriculum included home and personal management, food preparation and management, industrial arts, work experience on campus, mobility, job placement off campus, and use of leisure time. The typical schedule involves the young adult spending half a day in the residence learning and applying home management skills such as food preparation, shopping, and cleaning and half a day in a job-oriented training session.

Midwest Regional Center Activities

Using the services of Opinion Research Associates, the Midwest Regional Center for Deaf-Blind Children, Lansing, Michigan, conducted a region-wide planning program. The focus of this program was to report prevocational training needs of the total population of deaf-blind individuals in potential employment settings. Eight meetings were held in the region. The meetings addressed the current and future needs of deaf-blind persons as perceived by parents, educators, and guardians. Of the 643 needs identified, 23 percent clustered around the current need for full-time educational services which focused on basic living skills, communication, and mobility training.

In terms of future needs, 25 percent of the prioritized responses centered on the need for specific types of alternative living options for adults who were deaf and blind. These options

would need to be responsive to the person's level of functioning and flexible in assigning the person to a living arrangement as well as in encouraging future placements which would better suit the needs of the client.

A second phase of the study was to identify service agencies that are or could be serving deaf-blind persons in the Midwest region. By questionnaire, 441 agencies were asked if they could provide prevocational services to deaf-blind youth and adults. Of the 249 questionnaires returned, 92 agencies said that they were providing services to deaf-blind persons currently and could modify their programs for future needs of this population. These agencies indicated a willingness to serve or modify their programs to serve low functioning deaf-blind persons. Fifty-seven agencies replied that they were not currently providing services to deaf-blind persons, but that they would be willing to do so. These agencies indicated that they could modify their programs to serve a wide range of level of functions, including low functioning persons. Ninety-four agencies reported that they did not provide services to deaf-blind clients and did not see the possibility of doing so in the near future.

A third phase of the study utilized the Delphi technique to ask professionals what characteristics deaf-blind clients needed to exhibit to be able to enter prevocational or vocational settings; what staff needs, resources, or special equipment would be needed in providing potential employers means by which deaf-blind persons could enter the job market; and what characteristics could be defined regarding job employment opportunities for deaf-blind persons. Four needs emerged from the Delphi process:

1. The need to join forces with those teaching and training the retarded. This may be interpreted as joining efforts with national organizations and state level organizations to work on common goals.
2. The need to make generalizations while maintaining an individual approach. This may be interpreted as a desire to keep the individual's needs as the focus of services while trying to use all existing resources to provide appropriate services to this population.
3. The need for a common behavioral language. This may be taken to mean that the behavior of each individual needs to be described but that it should not serve as a predictor of future levels of function or permanently mark a person at a static function.

4. The need to develop training facilities to serve deaf-blind persons. This may be taken to mean that during the joining of efforts with other groups to meet common goals, the needs of the deaf-blind person should not be ignored. Specific program services are needed which are unique to the person who is deaf and blind.

Mid-Atlantic Regional Center Activities

A pilot project was begun by the New York Institute for the Education of the Blind to provide prevocational services to students in that program. The project staff developed a curriculum guide, a video presentation of the project, and assessment protocols for simulated work activities (sorting, packaging, and assembly). The objectives of this program included evaluation and improvement of independent living skills, work habits, and work skills and the development of appropriate communication skills and age-appropriate socialization skills. The program also sought to develop age-appropriate recreational skills. When the deaf-blind student was enrolled in the prevocational program, contact was made with social and rehabilitation agencies in the person's home community, and the parents of the student were involved in planning for the future. This program not only provided training slots for students learning to work with adolescents who were deaf-blind but also provided for dissemination of the results of the study through the New York Institute.

South Central Regional Center Activities

In the development of regionalized efforts to provide services to deaf-blind persons, a continuum of services has been proposed (Hammer, 1974). This lifelong range of service options was developed (1) to orient service efforts toward specific goals; (2) to provide to all those interested in providing services to deaf-blind children an overall guide to options which would be needed; (3) to unify strategies among program services; that is, to reduce duplication of programming and to utilize all existing resources; and (4) to provide those working with deaf-blind children an idea of how their efforts related to the long-range goals of many other programs.

The continuum outlined several levels of services which spanned a developmental age bracket of approximately twelve years through adulthood. One particular program need was defined as the "Vocational Setting." Included in this category were two areas of training: prevocational services

and vocational training. Prevocational services in this continuum were operationally defined as those services necessary to provide a transition from the educational setting to an adult living situation. Included in this area of service activities were communication skills, socialization, self-help skills, attention to and completion of tasks, travel skills, and the academic skills needed to follow directions and to exhibit some level of independent function in a work situation.

In an attempt to identify those existing resources capable of providing the services which have been outlined in the continuum (Hammer, 1974), a cooperative interagency committee in Texas explored the programs in four major metropolitan areas of that state to see what local resources existed and what modifications would be necessary to make extended services or prevocational training available to deaf-blind children and youth. The members of the committee represented the state education agency, including consultants in visually impaired services and vocational education, the state services for the blind, and the state vocational rehabilitation agency, as well as public and private agencies currently serving deaf-blind persons. The cochairpersons of the committee were representatives from the state agency for services to blind persons and the state agency for vocational rehabilitation. In each of the four communities, all agencies known to have interests in working with either deaf, blind, or deaf-blind persons were asked to attend the meeting held in that metropolitan area. The problem of planning for extended services to the current population of deaf-blind children was explained; and all agencies represented were asked to send a letter to the committee (a) to state whether or not they would be interested in serving deaf-blind persons in a prevocational program; (b) to indicate whether or not they had deaf-blind persons currently in training; and (c) to outline what their agency would need in the way of assistance to modify or strengthen their program to provide services to deaf-blind persons.

Committee members who visited the various programs in Texas encountered a willingness on the part of local program administrators to provide services to deaf-blind persons. Modifications of existing programs seemed to be minor when compared to this interest in developing a needed service. The basic modification involved the coordination of services among these agencies so that existing prevocational training program personnel were aware of the deaf-blind population and their

future needs. The agencies also need assistance in staff development, particularly in manual communication for both staff and clients and the development of socialization skills for deaf-blind clients. Programs which would provide services needed to assist deaf-blind children in the transition from the educational setting to adult living situations were identified in each major metropolitan area of Texas (Hammer, 1972). In fact, from this series of meetings, four programs specifically designed to provide prevocational services to deaf-blind youth and adults were developed and are now in operation.

A regionwide workshop was held by the South Central Regional Center to assess the service needs of persons in vocational rehabilitation. From this meeting, a network was outlined for referral of deaf-blind clients among agencies so that duplication of effort would be minimized. A pilot prevocational program was begun at the Callier Center for Communication Disorders. Programs were also developed among agencies for vocational rehabilitation services and adult living situations. The Dallas Lighthouse for the Blind and the Texas Commission for the Blind established a vocational rehabilitation program for deaf-blind adults. Staff training and support services were provided by the National Center for Deaf-Blind Youth and Adults and by the South Central Regional Center for Deaf-Blind Children. Planning was begun for a pilot program in prevocational services at the Children's Convalescent Hospital, Bethany, Oklahoma, and the Arkansas Enterprises for the Blind, Little Rock, Arkansas. The Higginsville State School is planning a prevocational program for deaf-blind children in Missouri.

A series of meetings was held in each state in the region to assess the priorities and concerns of parents, clients, educators, and vocational rehabilitation personnel. The results of this study indicated that the areas of concern for services were ranked as follows:

1. Socialization. The most frequently ranked category of need was in the area of socialization skills for the deaf-blind person. This need was expressed in terms of socialization experiences and opportunities, self-help skills, motivation of the individual toward independent function, and work experiences prior to enrollment in formal job training.
2. Communication skills. The second most-mentioned category of need was in the area of communication skills. This priority seemed to delineate the need for deaf-blind persons to

have communication skills so that interaction might take place, as well as the need for professionals to have the skills to communicate with deaf-blind clients.

3. Community resources. The third category was in the area of community awareness and use of existing community resources, including administrative commitment to develop and provide services to deaf-blind persons, centralized coordination of services and planning, advocates for services, lobbyists to present the needs to decision makers, and the relationship of educational and vocational rehabilitation training programs clearly defined.
4. Specialized personnel. A fourth category centered on the need for specialized personnel to work with deaf-blind youth, families, and communities. This need was also expressed in terms of special programs for training personnel, either through college-level training programs or through inservice training programs. Special services in terms of parent counseling, physiological assessment of work skills, and individualized planning were mentioned in the group discussions.
5. Special materials, special facilities. Respondents also included the need for special materials, particularly in the area of assessment of potential function of deaf-blind youth as they approached adulthood. Special materials were needed to assist educational personnel in providing prevocational experiences to deaf-blind youth. Special facilities were mentioned as part of the need as well as unique placements for the deaf-blind person to move toward independent function. The child's right to education and the youth's right to appropriate vocational training were included in these priorities, as well as the need for appropriate transportation services to deaf-blind youth to attend programs.

From the data, two pilot programs for prevocational services were established in the region. One was located at the Children's Convalescent Hospital in Bethany, Oklahoma. This was an extended service program offering four major areas of training: (1) safety; (2) language; (3) sensory training; and (4) personal and social development. This program's function was to work with other educational agencies to provide extended services to children who were in need of more than the educational program offered. Thus, a child might be in an academic program during the day and attend the extended services program on weekends

or during the day after school hours. Deaf-blind youth who need more services may also be assigned to the program throughout the week. Residential services are also available. This program serves deaf-blind youth and adults in the metropolitan Oklahoma City area.

A second prevocational services program was established at the Higginsville State School and Hospital, Higginsville, Missouri. This program was designed to serve 14 deaf-blind students between the ages of twelve and twenty-one years. The program revolves around work activities, activities of daily living, recreation activities, and parent and foster parent services. The underlying intent of this program was to establish in a typical school/hospital for mentally retarded children a prevocational services program that had the potential to serve deaf-blind children and youth. Evaluation of this program will center on the types of materials which could be adapted to meet the perceived needs of the population, the progress made in socialization of deaf-blind students as a result of receiving additional services, and the modifications which would be needed to develop a prevocational program for deaf-blind youth and adults in a residential setting.

Northwest Regional Center Activities

The Northwest Regional Center for Deaf-Blind Children conducted a survey of facilities to find those capable of providing prevocational and vocational training to deaf-blind persons. Following this survey, initial programming was begun to integrate deaf-blind persons into vocational training programs. Further efforts will be made to utilize local program resources to provide prevocational services to deaf-blind youth in this region.

Summary

In seven of the ten regions, various activities have been undertaken to define the needs of deaf-blind adolescents in the transition from an educational setting to acceptance into a full range of adult living situations. While these efforts are only a beginning, they offer the hope that relevant services will be developed throughout the nation. One could appropriately view the state of the art in the area of prevocational services in a positive manner. The activities summarized in previous paragraphs indicate that the original inquiry goals have been addressed. The needs of the population have been defined, awareness of resources needed to provide services has been achieved, and initial programs in local areas are beginning to serve the

adolescent population. Personnel in vocational rehabilitation have been made aware of the needs of deaf-blind youth and adults and have responded in a positive manner in offering to develop services appropriate to this group.

However, the picture is not complete without including additional activities being conducted outside regional centers for deaf-blind children. The current literature includes reports of three studies which have direct impact on prevocational services to deaf-blind children and youth. The "1980 Is Now Conference" (1974) is certainly important in pointing to the need for forward thinking by those providing services to deaf-blind persons. However, the preliminary evidence from the Abt study (1974) indicates that future planning has a relatively low priority in developing services to severely impaired children and that the tendency is to serve fewer rather than more of these severely impaired children as they grow older.

If this evidence proves to be true for deaf-blind adolescents, the concept of services to deaf-blind children, which has emerged over the past few years, will be negated. Planning and programming must continue for deaf-blind children as they grow older. While most of the program development in the past five years for deaf-blind children has emphasized case-finding and primary academics, the shift in the age and needs of the population require that programs be modified to meet the needs of all deaf-blind children as they grow older. A need for early childhood programs, for home programs, and for programs which emphasize academic opportunities will remain. An even greater need will be to ensure that future needs are met with appropriate program services and that these programs continue as long as the deaf-blind person needs services.

A study conducted by the Rand Corporation (Kakalik and Brewer, 1974) raised the issue of whether the regional centers could change enough to provide full services. Regrettably, this study generalized from a very small sample in trying to develop the concept of a regional direction center to facilitate services to handicapped children. The study would have been more productive, perhaps, if it had detailed how existing resources, such as regional centers for deaf-blind children, could be utilized to facilitate services. This would have directed attention to the need for any regional program to have the time to plan instead of being limited to immediate issues. This would have

directed prospective regional direction centers toward coordinating resources and utilizing the legislation and litigation in existence to facilitate services. Such a recommendation would have been beneficial to regional centers for deaf-blind children in directing efforts toward assurance of quality services to deaf-blind persons throughout their life span. By law, the regional centers are limited to serving the population twenty-one years of age and under. The regional centers will do well to meet this goal. Yet, at some time the regional centers must develop cooperative efforts to ensure that services continue as the deaf-blind child grows older. The issue does not seem to be whether a framework exists for coordination of services; the issue seems to be whether the delivery of services will be relevant to the population to be served. Perhaps the encouragement of coordination of efforts, the elimination of duplication of efforts, and the utilization of existing frameworks would be worth pursuit by those responsible for ensuring the delivery of services relevant to the shifting needs of the population. In this manner, current programs would be required to utilize resources such as the career education programs, the Vocational Rehabilitation Act of 1973 and its amendments, Part 625 of the Education of the Handicapped Act, as well as the Supplemental Security Income and related Social Security amendments, the National Center for Deaf-Blind Youth and Adults, and the state comprehensive education acts.

Only through the exploration of future resources, investigation of service gaps, and clear definition of the needs of the population will services which are beginning to emerge for adolescents and youth who are deaf-blind continue to be relevant. If all resources can be melded into a clear picture, if the points of activity really do join together to make a whole picture, continuing services will be achieved. This truly seems to be the most pressing challenge to programs offering services to deaf-blind children in terms of immediate and long-range needs. The parts are there. They need only to be fitted into a total, responsive service to meet the needs.

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Vocational Rehabilitation for Deaf-Blind Youth and Adults

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Throughout the nation and, in fact, the world, the overwhelming problem inhibiting efforts to offer vocational rehabilitation services to deaf-blind people has been the inability to believe that these efforts would be successful. Few people believed deaf-blind individuals could be prepared to enter or reenter the employment market.

Statement of the Problem

The professionals responsible for administering rehabilitation services to the deaf or the blind have generally considered the cost of sponsorship and the unpredictable results to be unacceptable. They used the rationale that the money could be spent on others less handicapped, thereby enabling them to serve more handicapped people. Deaf-blind people themselves often did not feel that they could return to work or benefit from rehabilitation services, and they remained at home where they were cared for by relatives.

Yet vocational development or habilitation following the onset of any handicap is part of the ongoing process of human growth. It is not an isolated process. Much of the success in the guidance of someone toward a vocational goal must in many instances build upon the individual's life experiences. The onset of the handicap, the education, and the life-style of the individual, in many instances, are a barometer of the individual's future success. However, the complexity of nature and the inner resources and drives of the human being make it imperative that each person be given adequate vocational evaluation and counseling. Each deaf-blind person must be seen as a total individual, and a plan for vocational development or rehabilitation must be developed that would maximize his or her skills and enable him or her to secure the best employment opportunity possible.

Each deaf-blind person is not only unique from all other deaf-blind individuals, but she or he, unlike most other handicapped people, has for most life experiences depended upon external resources for his or her well-being. Psychosocial appearance and readiness for vocational training is often a reflection of the past services extended, and agencies, in developing or initiating vocational services for the deaf-blind, must be prepared to help adults who may lack education and early developmental experiences and who may come to the agency after many years of almost total isolation and, for all practical purposes, without any means of communication.

Past Efforts at Rehabilitation

Since the loss of sight and hearing is so isolating, social and recreation training must be an integral part of any comprehensive program. The person with the total loss of both sight and hearing is the only handicapped individual who cannot sit passively and be entertained. For this reason, he or she must learn the skills that would enable him or her to constructively utilize the after-work hours; otherwise, a seemingly successful placement can quickly become a failure.

The Industrial Home for the Blind

Although efforts on behalf of the severely handicapped have increased substantially since World War II, the Industrial Home for the Blind of Brooklyn, New York, has stood, until very recent years, virtually alone in the belief that deaf-blind people could benefit from rehabilitation services and enter into employment.

The Industrial Home for the Blind has offered employment to deaf-blind people in its workshops since 1920, but it was not until 1945 that the need

for a formalized training program was recognized.

The deaf-blind population at the Industrial Home for the Blind needed a special department to develop a more comprehensive program of services, to enable deaf-blind clients to more adequately utilize their leisure time, and to more advantageously utilize the other services offered.

On June 27, 1945, at the formal opening of this department, Helen Keller made the following statement:

During about a lifetime it has been the desire of my heart to find a friend with means and sympathies big enough to take in the unsheltered, uncomfited exiles of the silent dark, and now Heaven smiles upon me as I witness my long prayer answered in the deaf-blind people here who are loved, who work and sing at their tasks though outwardly mute.

Trainees for the first formalized rehabilitation training program were referred to the Industrial Home for the Blind from various parts of the country. Most of these trainees were congenitally deaf and adventitiously blind (Usher's syndrome). Since existing workshops for the blind or the handicapped showed virtually no interest at that time in the employment of deaf-blind people and there were no opportunities in competitive industry, most of the deaf-blind persons referred to the Industrial Home for the Blind were employed in its own workshops and lived at its residence.

Between 1956-1958 the Office of Vocational Rehabilitation conducted a study of the program for deaf-blind persons at the Industrial Home for the Blind. One of the major findings of this project was that deaf-blind people could be served best through regional centers. Because of the relatively small number of deaf-blind adults, most workers had great difficulty in gaining the knowledge and skill necessary to work with this group. Some workers would have only one or two deaf-blind clients throughout their career. Also, because of this lack of experienced personnel, local rehabilitation centers could not readily accept deaf-blind clients into their programs. Regional centers appeared to represent one way to bring together the number of trainees necessary to develop a staff with the experience necessary to gain both confidence and competency.

Funds were made available at that time by the U.S. Department of Health, Education, and Welfare to develop regional rehabilitation centers for the adult deaf-blind. However, only the Industrial Home for the Blind responded to this appeal and in 1962 joined with the Social Rehabilitation Service

to establish the Anne Sullivan Macy Service for deaf-blind persons.

The Anne Sullivan Macy Service

The Anne Sullivan Macy Service project was structured to serve a 15-state area from Maine to North Carolina, but adults from outside the area would be served if they could be fit into the program and if no local resources were available to them.

The major objectives of this service were fourfold:

1. To demonstrate a pattern of comprehensive services that would maximize development of the rehabilitation potential of deaf-blind adults
2. To demonstrate the ways in which state and local rehabilitation agencies could cooperate with each other and with the regional service to the deaf-blind, thereby paving the way for development of ongoing community-based rehabilitation programs for this client group
3. To conduct programs of research and study that would add to the sum of knowledge about the deaf-blind and how their rehabilitation could best be accomplished
4. To establish tested service and administrative procedures on a regional scale that might stimulate and guide the establishment of similar programs in other parts of the United States

The Anne Sullivan Macy Service was originally scheduled as a five-year project planned to terminate in 1967, but it was continued for two additional years in anticipation of the development of a national service. During the closing months of the project, a follow-up survey was made of the 171 clients who had received partial or comprehensive rehabilitation services. The survey was designed to ascertain their social and vocational status after rehabilitation.

Not all of the 171 clients received comprehensive rehabilitation experience. In some cases this was because clients did not need more than a few specific services and, once identified, these services could be provided by the local community. In other instances, clients did need and could have benefited from comprehensive rehabilitation but were not able to leave their communities due to family reluctance or lack of agency sponsorship.

The client case load was not hand-picked. The project accepted all who met the gross criteria of deaf-blindness. Indeed, any doubts concerning

eligibility or feasibility were resolved in favor of accepting the client. The median age of those served was close to 50, so it may be correctly inferred that half of the Anne Sullivan Macy Service clients were in advanced middle age or beyond.

Looking at the overall picture, the follow-up survey demonstrated that the effects of rehabilitation tend to persist over a long period and that the benefits achieved through rehabilitation can be expected to continue indefinitely if the proper service supports are made available in the community. The Anne Sullivan Macy Service had not only benefited the number of deaf-blind people it served, but its success was evidence that a national program in cooperation with other agencies throughout the country was feasible.

The National Center for Deaf-Blind Youths and Adults

An amendment to the Vocational Rehabilitation Act of 1967 established the National Center for Deaf-Blind Youths and Adults to provide services to deaf-blind youths and adults and to those agencies offering service to this group, and the Industrial Home for the Blind was selected to operate the center which started in June 1969. The center currently has five field offices throughout the country and affiliation with three other agencies is under consideration.

Eligibility for entrance into the rehabilitation training programs is limited to those deaf-blind persons whose visual and hearing losses fall within the following definition:

Deafness is defined as a chronic impairment of hearing so severe that most speech cannot be understood, even with optimum amplification. Blindness is defined as central visual acuity of 20/200 or less in the better eye with corrective lenses or central visual acuity of 20/200 if there is a field defect such that the peripheral field has been contracted to an extent that the widest diameter of visual field subtend an angular distance no greater than 20 degrees.

The single major functional criteria for entrance into the national center training program is that the individual can care for his or her personal needs. Entrance is not based on an educational or language requirement.

Obviously, one or two facilities cannot be all things to all people; therefore, the policy of the national center from its inception has been to encourage other agencies and their workers to develop much-needed services in their local area. With the encouragement, support, and active help from the regional representatives, many agencies

are now rendering the type of service they did not consider possible four or five years ago. Regional representatives are always available to any agency, for consultation, staff activities, development of communication skills, assistance with a specific client or case conferences, and so forth.

The national center offers a one-week program of Training in Services to Deaf-Blind Youths and Adults to workers who are likely to work with deaf-blind persons. This program includes four and a half days and three evenings of training: lectures, seminars, observation, and practicum. It develops a useful degree of expertise in serving deaf-blind persons. The participant becomes more confident in his or her ability to serve the deaf-blind and more aware of the feasibility of serving them.

In addition, the community education department of the national center recognizes the role of the press and other media in developing increased interest in the deaf-blind. Pamphlets explaining the services offered are distributed, and the department publishes the *NAT-CENT NEWS*, printed in large type and braille for deaf-blind people around the country. The national center also transcribes the *New York Times* daily news resumé into braille for nationwide distribution to deaf-blind people. In addition, devices specially adapted for deaf-blind people are stocked for use at the national center.

Research is still in the beginning stages. Currently research is directed toward the development of devices that are needed by deaf-blind people to enable them to lead more active and independent lives.

The national center also has responsibility for compiling a national register of the deaf-blind children and adults in the United States. One of the anticipated benefits of the register is that it will help to determine the types and extent of services needed for the number of deaf-blind children requiring adult services in the 1980s.

The Anatomy of the Rehabilitation Process

Rehabilitation training is a step-by-step process which builds upon the experiences of the individual and the progress made in the program. The five steps in vocational rehabilitation include: (1) pretraining evaluation and planning; (2) prevocational training; (3) vocational training; (4) placement; and (5) follow-up. Although all of these steps can take place in one facility, more likely several facilities will need to be utilized.

For many deaf-blind people who function on a low level and whose tolerance for change is low,

the desirable situation would be to avoid movement to different facilities unless absolutely necessary.

Pretraining Evaluation and Planning

To determine the vocational rehabilitation plans for any deaf-blind person seeking help, one should know not only the individual's aspirations but also what skills and abilities the individual has. In most instances, deaf-blind people have no idea that they are employable.

Regardless of the vocational goal of the client, the counselor must stress the need for the deaf-blind person to meet at least the minimum criteria for acceptance into further training programs or entrance into a specific vocational program.

Although some planning can be accomplished by workers meeting for the purpose of discussing direction and alternatives, evaluating the deaf-blind person's skills and potential for employment cannot be an armchair decision. Every individual has a right to the services of professionals skilled in making these assessments in a facility in which the individual can demonstrate his or her ability.

The pretraining evaluation is designed to determine the individual's readiness to move away from home to a center and to determine whether he or she meets the entrance criteria of the rehabilitation center. If the individual does not show a readiness to leave home or does not meet the entrance requirements, a program in the home should be planned for him or her.

Evaluating the deaf-blind person has to be as exact as possible because the deaf-blind person has virtually no opportunity for a second evaluation. To determine that a person is incapable of moving into a training program may condemn that individual to a life of idleness. An error in assessment may place the individual in an unhappy situation or direct him or her toward a goal that he or she could never attain.

The evaluation, which should take place in a center, is designed to determine whether the individual can proceed toward his or her objective and to determine what type of training is required. It should also serve to suggest alternative goals if the individual proves incapable of achieving his or her objective.

The evaluation process at the national center for a deaf-blind person is a six-week program that covers the following areas: (1) mobility; (2) activities of daily living; (3) domestic science; (4) communication skills; (5) work activities; (6) home repair; (7) physical condition; (8) speech; (9) hearing; (10) vision; (11) general health; (12)

medical; and (13) psychological adjustment (see page 216 for an outline of skills tested in each area).

• Prevocational Training

Prevocational training conventionally consists of vocational guidance, vocational exploration through observing and/or actually sampling occupations, and learning and applying the principles of time and motion economy and of safety at work. Such elements of prevocational training have application to the training of deaf-blind youths and adults, but they require imaginative adaptation. They must also be supplemented with intensive training in many areas of general functioning which ordinarily provide only a minimal challenge to the nonhandicapped youth and adult. A deaf-blind person with neither useful hearing nor sight must be literally trained to maintain his or her equilibrium, to walk with a normal gait, and to tactually use reference points in his or her environment effectively. The trainee must be helped to develop tactile perception of kinesthetic learning and kinesthetic memory. A deaf-blind youth cannot learn work discipline as easily as the nonhandicapped youth. He or she cannot learn it by observing the behavior of others at work. Therefore, he or she must be taught the importance of applying himself or herself adequately and consistently to his or her work, the importance of remaining at work for the prescribed periods of time, the importance of resisting distractions, and the qualitative and quantitative requirements of the work. Danger points in the work position and in the general work environment must be pointed out to him or her, and care must be taken to be sure that he or she knows how to avoid them and understands the consequences of failing to avoid them. The deaf-blind youth, too, must learn to communicate with the nonhandicapped co-workers and supervisors through methods that do not require special training on their part. He or she must learn to tolerate the slowness of such communication, to cope with the frustrations induced by those limiting conditions of his or her handicap that cannot be reduced, and to accept with good grace the occasional thoughtlessness of co-workers and supervisors. In essence, he or she must understand and deal with the reality that his or her acceptance by others and his or her ability to make a contribution at work and in his or her community will depend on his or her readiness to go more than halfway in accommodating others and in developing their goodwill.

Much of the content of a prevocational training program is important to everyday living, and, consequently, every deaf-blind trainee should be provided with prevocational training adapted in scope and intensity to his or her special abilities and needs.

Prevocational training may be defined as training designed to develop readiness to engage in either vocational training, skilled work, higher education, or remunerative employment in semiskilled or unskilled work and to meet the social demands entailed in the successful pursuit of remunerative employment regardless of the skill required to perform the work itself.

No rehabilitation center can hope to maintain the staff and facilities necessary to provide competent instruction in all of the vocations into which deaf-blind individuals may enter. The responsibility of any rehabilitation agency serving deaf-blind individuals is to be prepared to refer these persons to the appropriate facility.

On the basis of the evaluation and recommendation of the staff, the trainee is assigned to an individualized training program. This program is designed to eliminate weaknesses, to refine skills, to provide opportunity to experience work tasks, and to develop a healthy attitude toward employment. Through supportive rehabilitation counseling and casework services, the individual works through his or her feelings toward his or her handicap and is helped in taking part in realistically planning future vocational goals.

Vocational Training

Vocational training opportunities for the deaf-blind are extremely limited. For most deaf-blind people, vocational training will consist of work experience or on-the-job training in a workshop setting or in a competitive placement. This provides the trainee with a specific skill and provides the counselor with the opportunity to observe the work performance of the individual within a work setting. It will be up to the counselor to continue the assessment of the individual in relation to the standards of the workshop or potential employer.

Observation is made of the individual's attitudes, attendance, punctuality, and quality and quantity of work. In addition, the counselor has an opportunity to observe the individual's general work habits and functioning at and away from his or her work station.

A trainee may be sent to one of the Industrial Home for the Blind workshops for this work experience when he or she reaches a point at which

either vocational counseling or social casework is no longer necessary. Ultimately the trainee's work performance and conduct at work determines his or her capabilities for working in a workshop or in competitive employment.

Although many work tasks in a workshop may be of an industrial nature, they provide the imaginative counselor the opportunity to determine whether the individual has the potential resources to be a candidate for office-type employment or to enter into an educational program.

For those who have academic backgrounds, educational facilities may provide the type of education or training necessary to prepare the deaf-blind person for a specific professional career. At best, college work for deaf-blind people, even those with useful vision, is difficult. Special assistance must be given for interpreting in class and after-school studies. Few people are aware of how enormous the task is for the totally deaf-blind person to attend college and participate in a satisfactory manner. Success usually requires a minimum of four hours of supportive services for every one hour of school attendance by such an individual.

Placement

When all the data are gathered and the client's training is almost finished, the national center's rehabilitative counselors increase the frequency of their contacts with the referring counselor. The referring counselor, until this time, has been kept informed of the client's progress, and evidence has been developed regarding the type of placement that will be appropriate. By this time, decisions have been made relative to the specific type of employment most suitable for the individual consistent with his or her educational, vocational, emotional, and social development.

Competitive employment falls within four major categories: (1) industrial employment; (2) white collar employment; (3) professional employment; and (4) self-employment or family business. The work tasks included in these categories might be unique and quite possibly one-of-a-type, since they fit into the special skills, background, and locale of the client. The types of jobs available in competitive industry include the following:

Industrial

Automatic power press operator
Bench assembly worker
Bookbinder

Boring machine operator
Bulk mail handler
Bus boy
Circuit board assembler
Counter sinking
Deburring—hand and lathe
Dishwashing machine operator
Drill press operator
Electric screwdriver operator
Electric stapling machine operator
High speed assembly line (bicycles)
High speed boom operator
Hospital kitchen worker
Laundry worker*
Milling machine operator
Mimeograph machine repairperson
Mop winder
Soldering worker
State vending stand worker
Subassembly worker
Tapping machine operator
Tube polisher

White collar work

Braille proofreader
General worker, braille library
Heavy duty mail handler
Mailroom worker
Office worker
Retail salesperson
Thermaform operator

Professional work

Administrator
Computer programmer
Public relations worker
Rehabilitation teacher-counselor
Student guidance counselor
Teacher-correspondence worker
Teacher's aide

Self-employed or family business

Chair caning
Egg producing business
Farming
Handicrafts

*Includes: flat iron feeding and receiving, sorting and separating lines, and folding.

Many deaf-blind individuals can develop enough skill to work in an industrial setting; a few can achieve enough skill or education to become employed as white collar workers. Occasionally an

individual will be capable of obtaining a professional position. The greater majority of deaf-blind people will be incapable of succeeding in white collar or professional employment, but some will be capable of performing job tasks similar to their sighted and hearing co-workers.

Although the Anne Sullivan Macy Service achieved a breakthrough by placing a number of deaf-blind people in competitive employment (and the national center has achieved greater success in this area), workshops still offer the best opportunities for the greatest number. More recently work-activity type workshops have become a recourse for those who are unable to meet regular workshop standards.

Whether placement is in a workshop or in competitive industry, the individual must be motivated toward employment and have an interest in and an awareness of quality and production standards. These characteristics are minimal for workshop placement.

Peter Salmon, speaking to the National Rehabilitation Convention (1958), made the following comments regarding the characteristics of deaf-blind people in competitive jobs at that time:

1. They are emotionally ready for competitive employment.
2. They have mobility.
3. Their skills are adequate.
4. They retain some useful vision. (Relatively few totally deaf-blind persons continued to maintain successful competitive employment.)
5. Their blindness is slowly progressive rather than of sudden onset.
6. They tend to be emotionally stable and well-integrated individuals.

We have observed a number of situations in which a deaf-blind person lacking one or more of these characteristics has still been able to achieve success in industry. In these instances, the deaf-blind individual had some special assets. Some of these assets were: (1) a special skill or talent highly desired by industry and usually developed prior to the onset of the second handicap; (2) unusually good manual dexterity; and (3) special transportation resources.

Placement at the National Center

Placement at the national center is unique because it is not done directly in most cases. The placement counselor's responsibility at the national center is to work with the professional staff and

help them prepare the client for job readiness. The placement counselor consults with the rehabilitation counselor to find out where the client stands with regard to his or her completion of the program.

The placement counselor must be aware of the client's total ability. This includes any physical limitation or ophthalmological restrictions as well as the individual's overall industrial functioning at a rate commensurate with his or her potential. Because the client does not always enter competitive employment, the placement counselor should be aware of the client's abilities for other types of employment. The counselor often must convince the sponsoring agency's counselor that his or her client has gained the abilities needed to enter some level of employment. The placement process then becomes a two-man team effort.

The sponsoring counselor is asked to take the initiative and establish employer contacts prior to the placement counselor's arrival in the home community. These contacts economize time and enhance the opportunities for placement. The sponsoring agency's counselor has been kept informed of the client's progress during his or her training by extensive and detailed narrative reports sent by the national center's vocational rehabilitation counselor.

The team approach to the placement process should be rehearsed by the individuals involved. In most situations, the sponsoring counselor is encouraged to take the lead in opening the conversation with the prospective employer. This discussion can vary but for the most part it should deal with the agency's involvement with the client and his or her sponsorship at the national center. At appropriate times during the initial contact with the prospective employer, the national center's counselor will often discuss the particular client's abilities and how the training program at the national center prepares the client to undertake the level of employment being sought. Both counselors should be prepared to cope with any objections offered by the prospective employer. In addition to this, the placement counselor from the national center will offer assistance with the plant survey and job analysis to assure the prospective employer that the client can negotiate the plant. The counselor will point out the client's mobility skills and demonstrate during the job analysis how the client can perform the job. Some of the factors that are pointed out to the prospective employer are the client's possible performance and the built-in safety factors of any machinery and similar

operations performed during the training period. The prospective employer should be informed of the client's ability to transfer skills learned at the national center to an actual job in industry. The prospective employer should also be told if the job is not feasible for the client. However, the prospective employer should be encouraged by both counselors to continue to search for another job which might be feasible.

Following are three examples of how the placement counselor at the national center has become involved in the actual placement process:

1. Client (A) was nearing the completion of his training at the national center. He was a mature man with several years of experience as a clerical worker. His maturity and previous work experience did not warrant his receiving any practical work experience at a workshop during his training at the national center. Therefore, after completing all areas of training at the national center, he was to return to his home community and seek out employment.

In this particular case, the home counselor had little or no experience in placing blind people in competitive employment and none in placing deaf-blind persons. This alerted the placement counselor and his supervisor to the fact that placement might take longer because initial ground work would have to be done when the placement counselor arrived in the home community.

The client's abilities were known to the national center's placement counselor, and they were discussed in detail with the sponsoring agency's counselor. Through these discussions, the local counselor developed an understanding of the client's abilities and started to list agencies which could be contacted and should be helpful in offering suggestions on job leads. These agencies included the local employment service, the Chamber of Commerce, and a church organization. Through various periodicals, such as the State Employment Directory, newspapers, and personnel contacts, a job was found for the client in one week. The placement counselor at the national center offered to stay with the client during his first few days of employment. During this time the client was oriented to the job and the communication barrier was lessened because the placement counselor worked with the client's fellow

employees and supervisor, demonstrating the best means of communication with the client. After the national center's placement counselor was assured that the individual showed potential for meeting the competitive standards of employment for this particular company, he had a meeting with the counselor and management staff, assuring them that the client would be a good worker and producer. During this meeting he pointed out that the local counselor would be responsible for conducting a complete follow-up program. He would also be available in the event he was needed. The national center's placement counselor assured both parties that he, too, would be available, if needed.

2. Client (B) completed the national center's training program, was recommended for competitive employment, and returned to his home community. Unlike most of the clients who are sponsored by commissions for the visually handicapped, client (B) was sponsored by a general agency. Therefore, instead of the regular placement counselor responsible for placing handicapped people, the general counselor became involved.

Although the local placement counselor had many frustrations during the week in attempting to arrange employment contacts, he made the placement without the direct involvement of the national center's placement counselor. He had made both the plant survey and the job analysis. He made the decision to place the individual on the job on the basis of the report from the national center's vocational rehabilitation counselor and his discussions with the national center's placement counselor. Client (B) is involved in the group incentive plan in his department. He operates a counter-sinking machine, tapping machine, and multiple-spindle drill press. The local counselor conducts an extensive follow-up program and keeps the national center's placement counselor informed of the progress of client (B).

3. In the case of client (C), the placement counselor from the national center took still another approach. Again, the client returned home with the recommendation for competitive employment. However, the sponsoring agency's counselor had to work through the agency's placement consultant. Unlike the case of client (B), the counselor was involved

not only in the plant survey and the job analysis but was also involved in the preemployment physical, orientation, and personnel procedures.

The local counselor and the placement counselor from the national center convinced the placement consultant in the home community of the client's abilities. The placement consultant drew upon his own resources and accompanied the placement counselor from the national center and the local vocational rehabilitation counselor to a plant where he knew the personnel.

The plant survey and job analysis were carried out by the placement counselor from the national center. He decided that client (C) could perform the duties. This particular job involved operating a single spindle drill press. As the job analysis was being done, the national center's placement counselor was able to point out to the foreman and other plant personnel that the job could be performed by a deaf-blind individual. He gave each of the individuals a sample produced in the training program by the client.

After a commitment for employment was obtained, the local vocational rehabilitation counselor then assisted the client with his preemployment physical and personnel and orientation procedures. The national center's placement counselor stayed with the client until the client (C) had demonstrated the potential to meet the competitive standards required by the company. As in all cases, the local vocational rehabilitation counselor assumed the responsibility of a follow-up program.

The national center also responds to requests by other agencies for assistance in placement when a deaf-blind person has received rehabilitation training at an agency other than the national center. Before the placement counselor from the national center becomes involved in employer contacts, however, the agency making the request must convince the placement counselor that the client has the ability to meet the standards of that level of employment being sought. If this criterion has not been met, the national center's placement counselor will suggest that the rehabilitation agency make arrangements for the client to gain additional work experience.

The placement counselor's role often goes beyond employer contacts, plant surveys, job analysis, orientation of the client to the job, and direct

or indirect follow-up. He or she is often called upon to involve other agencies, such as agencies for the deaf/blind, church organizations, local service clubs, and social service agencies, in seeing that the resettlement and/or relocation proceeds as smoothly as possible. The overall goal is to have the client become a member of the community. The national center regional representatives assist in this process. This assistance by the regional representatives may precede the client's return to his or her home community, in which case it becomes a follow-through process for the placement counselor. The placement counselor can also initiate some social contacts, offer suggestions for future contacts, and ask the regional representatives to follow through.

Follow-up

A controversial point in placement services is whether or not professional contact should be maintained with the handicapped client once employment is secured. The policy of the national center, based upon years of experience, is that contact and/or observation of the employed deaf-blind person should continue. Follow-up contacts have proven to be as necessary as any other aspect of rehabilitation.

Through follow-up contacts, the counselor can often detect and correct a problem which was undetected or overlooked initially. Small problems may develop into problems which seem too large to be solved, and this may lead to the dismissal of deaf-blind workers.

Resources

The placement of deaf-blind people, whether in competitive employment, sheltered workshop, or work activity center, is still accomplished on a one-to-one basis. Placement is virtually assured when the agency or plant manager recognizes that an appropriate assessment of the individual has been presented, that the agency will receive help during the initial phase of training, and that assistance in developing communication skills is a part of the placement process. The manager must have assurance that hiring a deaf-blind person is a cooperative relationship and that he or she will have someone to call if he or she needs help.

Agency managers are quite often unaware that they have positions that can be filled by deaf-blind people. One role of the national center regional representative has been to evaluate potential resources to point out appropriate jobs for deaf-blind persons.

Many agencies have responded positively and have accepted the challenge of providing employment and rehabilitation services to the deaf-blind. As a result, the number of deaf-blind adults who are employed on a competitive level in these agencies and in private industry has greatly increased. Figure 1 shows the vocational achievements of deaf-blind adults.

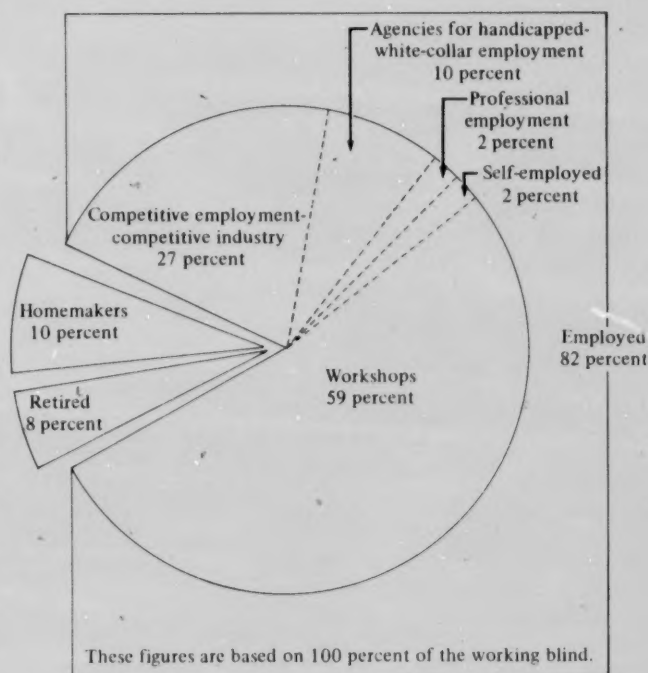


Fig. 1. Vocational achievements of deaf-blind adults

Every state has an agency which provides for rehabilitation training services or provides tuition for college education for deaf-blind individuals. These agencies may specifically serve the blind or may be a section in a division of vocational rehabilitation. The main office is generally located in the capital city with a number of local offices located throughout the state. A comprehensive list of these agencies and other agencies serving the blind is available in the *Directory of Agencies Serving the Blind*, which is published by the American Foundation for the Blind.

A number of rehabilitation centers and workshops throughout the country are beginning to show an interest in offering training and employment to deaf-blind persons. Current information may be obtained from national center regional

representatives. Centers for vocational rehabilitation training include the following:

National Center for Deaf-Blind Youths and Adults
Middle Neck Road, Sands Point, NY 11050
Regional Representatives

Western
102 North Brand Boulevard
Glendale, CA 91203

South Central
1111 W. Mockingbird Lane, Suite 825
Dallas, TX 75247

Eastern
1422 Chestnut Street
Philadelphia, PA 19102

Southern
134 Peachtree Street, N.W.
Atlanta, GA 30303

Midwestern
75 East Wacker Drive
Chicago, IL 60601

Affiliated Agencies

Arkansas Enterprises for the Blind, Inc.
2811 Fair Park Boulevard
Little Rock, AR 72204

Services for the Blind and Visually Handicapped
1745 University Avenue
St. Paul, MN 55104

California Industries for the Blind, Inc.
840 Santee Street
Los Angeles, CA 90014

and
1255 Park Avenue
Emeryville, CA 94608

and
1344 F. Street
San Diego, CA 92101

Other Agencies

Alabama Institute for the Deaf and Blind
P.O. Box 698
Talladega, AL 35160

Arizona Industries for the Blind
3013 W. Lincoln Street
Phoenix, AZ 85009

Chicago Lighthouse for the Blind
1850 West Roosevelt Road
Chicago, IL 60608

Dallas Lighthouse for the Blind
4306 Capitol Avenue
Dallas, TX 75204

Michigan Rehabilitation Center for the Blind
1541 Oakland Drive
Kalamazoo, MI 49008

San Francisco Lighthouse for the Blind
1097 Howard Street
San Francisco, CA 94103

Seattle Lighthouse for the Blind, Inc.
2501 South Plum Street
Seattle, WA 98144

Virginia Rehabilitation Center for the Blind
401 Azalea Avenue
Richmond, VA 23227

Prevocational programs for teenagers are being established throughout the country under the sponsorship of the Regional Centers for Services to Deaf-Blind Children, and current information concerning programs available can be obtained directly from the regional centers.

Recommendations and Summary

Deaf-blind people in the United States and, indeed, throughout the world have perhaps been neglected and subsequently isolated from family, friends, and community. Rehabilitation efforts have been limited despite the fact that these services were so obviously needed. Although increased educational and vocational opportunities are now being offered to children, youths, and adults, a need still exists for advocacy to ensure increased involvement by the various disciplines offering services to the handicapped. Recognizing the irreparable damage to children who have had no opportunity for education, every effort should be made to ensure that all children reach adulthood as knowledgeable, skilled, and wholesome as possible.

Deaf-blind people have suffered too long from neglect and have virtually been pushed into areas of service or programs without any personal involvement in the plan. Each deaf-blind person should be treated with dignity and assisted in exploring for himself or herself his or her place in this universe.

Deaf-blind people, like everyone else, do not live by bread alone. To think solely in terms of vocational goals is not enough. To enable each individual to lead an active and happy life, he or she must be able to utilize constructively the time he or she spends away from work. Therefore, each

school or rehabilitation program serving the deaf-blind should include recreational and social experience that will provide the individual with the skill and confidence needed to be as active as possible with his or her family, friends, and co-workers.

Since changes always take place within each individual and within his or her environment, the customary concept of closure should not be applicable to deaf-blind clients, and needed services should be available at any time and as quickly as possible. If two or more agencies are involved in providing service, a coordinator or case manager should be assigned the responsibility for continuing contact or observation.

Extensive use of trained volunteers should be encouraged to provide the individual with the help or companionship he or she may need to enable him or her to maintain a level of involvement

consistent with his or her ability. Many deaf-blind people may require the services of groups serving handicapped people other than the deaf or the blind. Therefore, each state agency should assign a coordinator to look after the interest of each deaf-blind person within the state and to be the advocate for the development of increased services to the deaf-blind.

The complexity of problems related to the education and rehabilitation of deaf-blind persons will naturally result in differences of opinion regarding the preferred approach, method, or technique. These variations could be beneficial if they are looked at as the means to the end and not the end itself.

If we are to succeed in helping each deaf-blind person reach his or her maximum potential, we must recognize the need for constant evaluation of ourselves and our programs.

National Center for Deaf-Blind Youths and Adults
Evaluations for Vocational Readiness

COMMUNICATION

- A. Manual
 - 1. Manual alphabet
 - 2. Signs
 - 3. Print-on-palm
- B. Oral
 - 1. Lipreading
 - 2. Speech
- C. Print
 - 1. Reading
 - 2. Writing
 - 3. Script
- D. Equipment
 - 1. Typewriter
 - 2. Braille reader and writer
 - 3. Opticon
 - 4. Tactile telephone
 - 5. Pocket alphabet plates

GENERAL HEALTH

- A. Physical evaluation
 - 1. General medical
 - 2. Vision
 - 3. Hearing
 - 4. Fitness
 - a. Posture
 - b. Weight
 - c. Stamina
 - d. Muscle tone
 - e. Large muscle coordination
 - 5. Dexterity
 - a. Manual
 - b. Bimanual
 - c. Fingertip sensitivity
 - d. Fine motor grasp
 - e. Fine muscle coordination
- B. Psychological evaluation
 - 1. Attitude toward work
 - a. Frustration tolerance
 - b. Attention span
 - c. Learning ability
 - d. Fear of vibrating machines
 - e. Work habits and organization

MOBILITY

- A. Orientation
 - 1. Residence
 - 2. Training center

- B. Basic conditions of safety
 - 1. Walks steadily with proper body posture
 - 2. Uses points of reference effectively
 - 3. Knows precise location of objectives
 - 4. Localizes and interprets vibration and other stimuli effectively
- C. Street crossing
 - 1. Finds curb
 - 2. Squares corners
 - 3. Uses cane and/or guide in crossing
 - 4. Crosses without an aid (for trainees with useful residual vision)
- D. Transportation
 - 1. Auto or taxi
 - 2. Bus
 - 3. Railroad
 - a. Purchases ticket
 - b. Ascends and/or descends stairway
 - c. Stands on platform
 - (1) Island platform
 - (2) Single track platform
 - d. Gets on and off train
 - 4. Elevated or subway train
 - a. Uses change booth
 - b. Passes through turnstile
 - c. Ascends or descends stairway
 - d. Stands on platform
 - (1) Island platform
 - (2) Single track platform
 - e. Gets on and off train
- E. Buildings
 - 1. Revolving doors
 - 2. Escalator
- F. Use of sighted public
 - 1. Follows a guide
 - 2. Obtains information
 - 3. Interprets and uses information correctly
 - 4. Makes contact
 - a. Voice
 - b. Cane
 - c. Button
 - d. Card
 - e. Cues
 - 5. Refuses help graciously

DAILY LIVING

- A. Personal hygiene
 - 1. Shaves
 - a. Electric razor
 - b. Safety razor

2. Hair
 - a. Washes
 - b. Combs
 - c. Parts
 - d. Sets
 - e. Dries
3. Teeth
4. Fingernails
 - a. Cleans
 - b. Clips
 - c. Files
 - d. Brushes
- B. Personal appearance
 1. Clothing
 - a. Identifies colors and textiles
 - b. Hangs up clothes
 - c. Folds and packs
 - d. Washes
 - (1) Hand
 - (2) Machine
 - e. Dries
 - (1) Hangs clothes on line
 - (2) Machine
 - f. Irons
 - g. Hand sewing
 - (1) Buttons
 - (2) Hems
 - (3) Threads needle
 - (4) Uses tape measure
 - h. Machine sewing
 - (1) Threads
 - (2) Operates
 2. Shoes
 - a. Laces
 - b. Ties
 - c. Shines
 3. Neckties
 - a. Tying
 - b. Clip-on
 - c. Tie bars
 4. Make-up
- C. Shopping techniques
 1. Areas
 - a. Small stores
 - b. Supermarkets
 - c. Department stores
 - d. Cafeterias
 2. Identifies
 - a. Cans
 - b. Boxes
 - c. Bottles
 3. Money
 - a. Identifies coins and bills
 - b. Makes change
- D. Cooking skills
 1. Sharp utensils
 - a. Carries
 - b. Stores safely
 - c. Pares
 - d. Chops
 - e. Uses magna-wonder knife
 - f. Electric knife
 2. Follows recipe
 - a. Measuring cups
 - b. Measuring spoons
 3. Makes sandwiches
 - a. Spreads
 - b. Cuts
 - c. Arranges
 4. Uses stove
 - a. Light oven
 - b. Boil
 - c. Fry
 - d. Bake
 - e. Broil
 - f. Follow safety rules
 5. Appliances
 - a. Bottle and can openers
 - b. Mixer
 - c. Fry pan
 - d. Toaster
 - e. Broiler oven
 - f. Blender
 - g. Percolator/urn
 - h. Pressure cooker
 6. Dishwashing
 - a. Hand
 - b. Machine
- E. Eating skills
 1. Set table
 - a. Locates items
 - b. Sits down gracefully
 - c. Pours hot and cold liquids
 2. Table manners
 - a. Napkin
 - b. Bread as a pusher
 - c. Uses knife, fork, and spoon appropriately
 - d. Eats correctly
- F. Cleaning
 1. Floor
 - a. Carpet sweeper
 - b. Vacuum
 - c. Wet and dry mop
 2. Washes windows and mirrors
 3. Bed
 - a. Makes
 - b. Changes linen
 4. Bathroom

- a. Cleans
 - b. Arranges medicine chest
- G. Reads time
- 1. Clocks
 - a. Braille

- b. Print
 - c. Alarm
- 2. Watch
 - a. Braille
 - b. Print

Recreation for the Deaf-Blind

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One of the basic human and civil rights related to recreation, leisure, social, or cultural participation for the deaf-blind person is the assurance of equal opportunity for participation in programs and activities, complete access to public facilities, the right to inclusion in organizations providing recreation service, and the opportunity to explore fully and to achieve the highest potential in all human rights and endeavors.

Leisure has been defined by Kraus (1966) as "that portion of an individual's time which is not devoted to work or work-connected responsibilities or to other forms of maintenance activity which therefore may be regarded as discretionary or unobliged time."

He further defines recreation as:

... activities or experiences carried on within leisure, usually chosen voluntarily by the participant, either because of the satisfaction or pleasure he gains from them or because he perceives certain personal or social values to be derived from them. Like leisure, recreation does not have work connotations. When it is carried on as part of organized community or voluntary agency programs, it is designed to meet constructive and socially acceptable goals of the individual participant, the group, and society at large.

According to Nesbitt (1970) four basic reasons can be used in justifying special recreation services for handicapped children and youth.

1. Human and civil rights to recreation. The human and civil right of all people to participate in cultural, recreational, and leisure pursuits has been stated in formal declarations. Public recreational buildings, for example, have been required in recent years to provide barrier-free entrances and exits for physically handicapped (International League, 1968).

2. Normalization in recreation and leisure. Normalization for the handicapped, including recreation and leisure normalization, has already been accepted as a social policy in European countries and is increasingly being accepted as a social policy in the United States. In the years to come, normalization in recreation and leisure will become an increasingly prominent area of program support (Nesbitt, 1970).

3. Contribution of recreation to rehabilitation. Day-to-day experience as well as a growing volume of professional literature support the proposition that recreation participation contributes to the achievement of medical, social, educational, and vocational rehabilitation goals. The contribution may be indirect, as when a patient must have relief from the demands of an intensive rehabilitation program, or direct, as when social, cognitive, or physical skills gained or practiced in recreation contribute to a general rehabilitation plan (Nesbitt, 1970; Neal, 1970).

4. Therapeutic recreation service. Over the last 25 years, therapeutic recreation service personnel have developed a body of knowledge and conducted research that guides the present-day practitioner in organizing, administering, and presenting therapeutic recreation activities that make a definite contribution to recovery or adjustment relative to illness, disability, or specific social problems.

The recreation service provided to handicapped children and youth living either in the community or in institutions is limited. For example, in California, which lists approximately 150,000 registered handicapped children and youth from kindergarten through twelfth grade, only 3,000 are

reported as being provided community park and recreation department services. Further, only 2,000 of California's handicapped adults, including the aged, were reported as being provided community recreation and park services. The situation was summarized by Nesbitt.

Nesbitt (1972) found that no more than one-fifth of the nation's ill and handicapped are receiving any type of professional recreation and leisure service; the services provided are underfinanced and offered only infrequently; materials, equipment, supplies, staffing, and support services, such as transportation, are very limited.

Leisure is forced upon millions of ill and handicapped for whom there is no employment, limited employment, or only part-time employment. Enforced leisure has a different meaning for the nonworker than for the worker.

The challenge is to make enforced leisure into an experience in which the individual may achieve his or her maximum potential. The challenge to those serving the deaf-blind person is to manipulate the recreation environment to this end.

The aim of leisure education is to provide students with the competencies necessary to willfully direct their leisure occupations in a manner that is personally satisfying and fulfilling, culturally meaningful, and socially worthwhile.

The aim of special leisure education is to provide students with the special competencies necessary to overcome, adapt, modify, or in other ways achieve the goal of normal recreational, leisure, and cultural pursuits.

Therapeutic recreation services are based on the humanistic view that handicapped people are entitled to personal fulfillment in their leisure, just as the nonhandicapped are. When adaptation is necessary to make fulfillment possible, the adaptation should be made. Second, recreation and leisure activities are, in fact, physically, emotionally, socially, and intellectually therapeutic. Finally, exclusion of the handicapped results in social and cultural deprivation, an entirely preventable handicapping condition. How may this fundamental position be related to the person who is deaf-blind? The general aim should be to meet what may be construed as the reasonable expectation of clients, their families and friends, and professionals whose experiences suggest the potential which may be achieved.

Because the deaf-blind comprise a small and often remote population, the problem has received limited attention. Little attention has been directed to the deaf-blind by the recreation and

park service in general and therapeutic recreation service in particular. The literature contains little written evidence relative to the importance of recreation for the deaf-blind. Recreation service to deaf-blind should be given attention as has been the case with other categorical groups over the last 20 years. Nesbitt (1972) said "It can be stated unequivocally that: No rehabilitation, vocational rehabilitation, or special education, therapeutic, medical or treatment plan is complete without attention to the individual's recreation and leisure needs, rights, aspirations, and future settlement."

In joining the deaf-blind rehabilitation-education service team, the therapeutic recreation specialist should perform a number of functions. In relation to recreation fulfillment, the recreation specialist should assist with parent counseling, social case-work, child care, and community agency service to and for the deaf-blind. The goals should be to increase acceptance of the client, to enhance interaction, and finally to assist other workers in the performance of their functions.

In the educational realm, recreation should seek to enhance instructional goals in the following areas: (1) communication skills, both receptive and expressive; (2) daily living skills, such as eating, dressing, toileting, grooming, self-care, and hygiene; (3) mobility skills for ambulation, locomotion, and independence; (4) physical skills, including exercise, rhythm, motor development, and activities such as swimming; (5) sensory skills, using sensory perception—auditory, visual, tactile, olfactory, and taste; (6) the social skills of personal adjustment, interaction with others, group play, recreation, and field trips; and (7) environmental awareness and adaption skills through recognition and interpretation using tactile, visual, and auditory stimuli.

Professional Methods Relative to Individual Students

Client assessment is an essential element in any educational or recreation service that is rendered to deaf-blind and should be done on a daily and weekly basis so that the small improvements can be noted and recorded. The types of instruments that may be used include the adaptive behavior scales, physical education skills checklists, self-developed tests, and progression scales. Assessment of client progress in recreation functioning should be made in individual recreation activity and in group activity at home, at school, in free play, and in recreation. The critical element in a professional recreation program is the use of an individualized,

sequential intervention and evaluation plan. The critical element in a professional recreation program is the use of an individualized, sequential intervention and evaluation plan. This plan is based on the following basic linear therapeutic construct: (1) assessment; (2) diagnosis; (3) prognosis; (4) prescription; (5) intervention; and (6) evaluation.

Professional recreation specialists are concerned with recreation, play, sports, leisure activities, creative activities, and games. In terms of the individual student, a professional recreationist establishes specific ameliorative objectives which can be measured in terms of cognitive, affective, social, or physical development. A professional recreationist works with the interdisciplinary deaf-blind service team in contributing to the overall rehabilitation, education, and functional development of the individual who is deaf-blind. The recreation program that lacks these features is simply not a professional program.

Professional Methods Related to Groups of Students

The total recreation program includes a number of activities designed to meet the group needs of students. It operates on a daily, weekly, monthly, seasonal, and year-round basis. No less than the individualized recreation activities, the total program is designed to achieve specific objectives that contribute to the rehabilitation, education, and functional development of individual students. The program that lacks specific objectives based on needs and evaluation of the progress of individuals within the group is not a professional recreation program. And a nonprofessional program simply will not fulfill the recreation potential.

Current Status of Programs

A survey of 150 deaf-blind program sites identified throughout the nation was conducted by Howard and Nesbitt (1974). Questionnaires were returned for 65 sites. The following was reported by these sites relative to the current level of recreation programs that they were offering.

The data in Table 1 shows the predominant influence of the education aspect of the programs, the classroom and playroom being the primary recreation facilities used.

The predominance of education staffs primarily responsible for the recreation program is reflected in Table 2.

The necessary basic components of a recreation program (guidelines, budget, and staff) are absent in over half of those programs for which responses were received.

Table 1
Educational Aspects of Recreation Programs

Facility	Percent reporting use of facility
Classroom	85
Playroom	72
Swimming pool	51
Playground	48
Gymnasium	38
Integrated wards	26
Separate living units	23
Day care center	8

Table 2
Staff Responsible for Recreation Programs

Staff primarily responsible for recreation program	Number of programs
Teacher	27
Teacher aide	13
House parent	6
Adaptive physical education teacher	5
Director of recreation	4
Occupational therapist	3
Recreation specialist	3
Motor specialist	2
Swimming instructor	2
Physical therapist	2
Other staff	4

Specific Activities Currently Provided

Part of the survey previously cited was devoted to obtaining information on activities actually provided for children and youth in the deaf-blind programs. Forty-three local programs provided information on activities which are currently provided.

The specific physical education, exercise, program activity, or recreation activity reported by those sites having a recreation program are shown in Table 3.

Specific equipment needs vary from program to program, but the data in Table 4 show response

Table 3
Activities in Recreation Programs

Activity	Percent of programs
Gross motor activity	100
Fine motor activity	100
Walking	100
Running	93
Jumping	91
Riding tricycles	81
Coactive motor activity	79
Scooting	79
Swimming	79
Picnics	79
Hopping	74
Bus trips	63
Car trips	60
Skiping	58
Galloping	49
Camping	42
Sledding	33
Riding bicycles	33
Relays	26
Competitive games	23
Boat rides	23
Day camping	21
Overnight camping	21
Hiking	21
Ice skating	16
Diving	14
Skiing	12
Bowling	9
Pontoon rides	5

to the availability of certain items in the programs reporting having a recreation program.

Materials and activities used in arts, crafts, and handwork recreation programs are shown in Table 5.

The kinds of equipment used in rhythm programs and the percent of programs reportedly using such equipment are: records (100 percent); bells (98 percent); drum (98 percent); blocks (91

Table 4
Equipment Used in Recreation Programs

Equipment	Percent of programs
Balance beams	100
Mats	100
Balls	100
Sound makers	95
Tricycle	93
Wagon	91
Coloring materials	91
Slide	84
Set of steps	84
Mirrors	81
Maze	77
Lights	67
Sandbox	67
Trampoline	65
Benches	58
Walkers	53
Standing table	49
Bicycle	44
Pronation board	28
Styrofoam pieces	28
Tandem bicycle	21
Table games	46
Cards	16
Dominoes	12
Scrabble	9
Checkers	5
Chess	2
Chinese checkers	2
Other games*	

percent); cymbal (91 percent); speakers (vibration) (63 percent); and piano (58 percent).

*Includes: Candyland, Hi Ho Cherry O, Raggedy Ann, Happy Little Train Game, sorting board, peg board, tactile toys, Lotto, puzzles, blocks, flowers, Tiddly Winks, Bingo, ring sets, Uncle Wiggly, Matching Game.

Modified or adapted games include: Concentration (teacher made) Cards, Bingo, Checkers, Dominoes.

Table 5
Activities and Materials Used in Recreation Programs

Activity	Percent of programs
Bead stringing	100
Finger painting	100
Puzzle working	95
Clay modeling	95
Peg board activities	93
Crayon drawing	93
Ring stacking	91
Painting	91
Scissor cutting	86
Pasting	84
Coloring	81
Pencil drawing	77
Water color painting	63
Writing	56
Printing	42
Paper flower making	37
Weaving	30
Leathercraft	12
Oil painting	5
Knitting	2
Crocheting	2
Supplies used	Percent of programs
Paper	100
Scissors	100
Finger paint	100
Crayons	98
Construction paper	93
Newsprint	91
Beans	88
Rice	79
Oatmeal	74
Two-person scissors	49
Others*	47

*Includes: clay, lotion, creams, powders, bubbles, peanut butter, popcorn, sand, soap flakes, liquid starch, coffee grounds, and shells.

Activities Adapted to and for the Deaf-Blind

A natural inclination is to assume that certain activities will be suited to people who are deaf-blind. This natural assumption is a little like the inclination to speak loudly to a person who doesn't speak one's own language. The natural logic goes something like this: "If I yell at this Spanish-, German-, Polish- or other speaking person, the likelihood is greater that he or she will understand me." We have seen this occur on the streets of our metropolitan areas; we may even have done some of the yelling ourselves. Of course, yelling doesn't do any good. It also doesn't do much good to assume that some recreation activities are more appropriate for a person with a particular disability than other activities.

We have had the same tendency in vocational rehabilitation—to consider that people with certain disabilities would do better in certain jobs. Hopefully, very little of this kind of thinking goes on. People do well in particular jobs because of their basic interest, aptitude, training, and motivation. The same applies to recreation. Rather than trying to associate particular recreational and cultural activities to a person's handicap, the person should be encouraged to pursue his or her personal and individual destiny in recreational and cultural activities and to do the thing that he or she wants to do, not what is convenient or appropriate. Then, the handicapped person and those who want to help him or her should set about adapting the activity, the rules, the equipment, the facility, and anything else that needs to be adapted to make the activity possible. Adaptation takes imagination, creativity, initiative, flexibility, and perseverance.

The golden rule of recreation adaptation is: Thou shalt adapt any recreational or cultural activity to the degree necessary to make that activity feasible for the handicapped participant.

Evaluation in Recreation for Deaf-Blind

In general very little evaluation is made of the delivery of recreation and park services, and only limited use is made of evaluation of recreation programs and services for handicapped. Relative to recreation for deaf-blind, the professional recreation service view is that recreation administration, program, activity, and leadership should be assessed.

Howell (1975) has set forth the following general rationale for assessment and evaluation in recreation for deaf-blind children and youth:

The consumer's needs, desires, and interests should be evaluated and these needs should be reflected in program planning and the evaluation process.

The recreation staff should be responsible for executing various recreational activities at the client's level of participation and evaluating progress based upon behavior objectives.

The recreation administrator (supervisor) should be responsible for evaluating the recreational programs in terms of the consumer's needs and interests. He is further responsible for evaluating the programs in terms of hospital (institutional) objectives and goals. Evaluation of the objectives and goals of the recreation department is also necessary.

The institution should evaluate its programs in terms of meeting the total needs of the client, which include the opportunity to participate in self-actualizing experiences.

Program evaluation can be divided into two distinct groups: (1) people-oriented—consumer, staff, administration, and institution; and (2) activity-oriented, which is basically concerned with programs per se and the equipment and facilities utilized in these programs.

People-oriented program evaluation infers that program evaluation centers around the consumer and persons providing services to these consumers.

Activity-oriented program evaluation begins with an evaluation of the goals and objectives of the recreational programs offered. These goals and objectives should be based on a departmental/institutional philosophy.

Criteria for establishing an effective means of evaluating recreation programs must be determined. Some questions which will assist in developing criteria for program evaluation are as follows:

1. Is the purpose of the program to provide a quality or a quantity experience? To what extent?
2. Does the program ensure a growing, learning, sharing experience?
3. What carry-over value does the program have? (specific activities)
4. Does the program ensure the consumer the opportunity for success? For failure?
5. Does the program stimulate the consumer's imagination and development of skills?
6. Does the program provide the consumer with the opportunity to experience self-actualization?
7. How does the program improve the quality of life of the participants?

An Administrator's Guide for Development

From one to three years are required to develop a professional recreational program. This involves recruiting professional recreation personnel, providing inservice training, and developing a budget.

Unrealistic expectations relative to the time needed to develop a professional program serve to undermine the program's development.

Inservice Training

Recruiting personnel trained or experienced in working with deaf-blind persons and providing on-the-job training in recreation usually result in a nonprofessional recreation program with limited potential. However, very few professional recreation personnel have undertaken professional preparation to work with sensorily handicapped and, in particular, deaf-blind persons. The best means of providing professional recreation personnel for recreation programs for deaf-blind is to recruit professional, prepared, and experienced recreation personnel and provide them with special inservice training preparation to serve deaf-blind persons.

Professional Recreation Consultation

At the present time, primarily because of the impetus of the U.S. Bureau of Education for the Handicapped, a number of advances are being made in the development of professional recreation service. The best means of incorporating these developments into an ongoing program is through consultation. Thus, an important feature of the professional recreation service is the involvement of an expert consultant at least twice a year. This is supplementary to the participation of professional recreation personnel in state and national special education and therapeutic recreation professional conferences and meetings.

Minimum Recreation Personnel Standard

The initial appointment in a regional recreation service for a deaf-blind program is necessarily at the recreation consultant or recreation director level. Each position requires a master's degree and/or experience in therapeutic recreation service. Following this initial appointment other staff may be obtained or recruited at lower levels of professional preparation (i.e., recreation supervisor, recreation leader, and recreation aide/assistant). To employ less than masters degree-level, registered personnel results in a number of difficulties in upgrading both personnel and program.

In obtaining professional recreation personnel, the National Recreation and Park Association Personnel Registry and the Professional State Park and Recreation Organization should be used. Approximately 1,200 professional recreation personnel are registered. While the supply of such personnel is limited, to recruit other than profes-

Table 6
Levels of Recreation Professionals

Title	Registration standards	Typical duties
Recreation aide/assistant Therapeutic recreation assistant	Two years of successful full-time paid experience under the direct supervision of a registered therapeutic recreation supervisor or director or 200 hours of inservice training	Assists in leadership and instruction and/or group recreation activities
Recreation leader Therapeutic recreation technician	Associate of Arts degree from an accredited college or university or satisfactory completion of two years of college with a major in other related fields	Instructs, leads, and evaluates individual and/or group activities
Recreation supervisor Therapeutic recreation worker	Baccalaureate degree from an accredited university or college with a major in recreation or fields related to therapeutic recreation	Directs and supervises recreation program in hospital, rehabilitation institution, school, community, or private agency
Recreation director Therapeutic recreation specialist	Master's degree from an accredited college or university with a major in therapeutic recreation or master's degree from an accredited college or university with a major in recreation and one year of experience under a registered therapeutic recreation director	Plans and administers therapeutic recreation program in hospital, rehabilitation institution, private or community agency
Recreation consultant Master therapeutic recreation specialist	Master's degree from an accredited college or university with a major in therapeutic recreation and two years experience under direct supervision of a registered recreation consultant	Directs and guides the initiation, planning, development, and operation of therapeutic recreation activity programs; prepares students to work with ill, handicapped, and disabled persons; conducts research

sional personnel will result in undermining permanently the recreation program that is provided.

Miller (1970) has identified various levels of recreation professionals that can be used. Table 6 includes a description of the duties of those professionals and other relevant information.

The levels reflected in the table parallel the levels of professional registration implemented by the National Therapeutic Recreation Society, a branch of the National Recreation and Park Association. Registration means that the registered individual meets the minimum standards established for various classifications in the therapeutic recreation field.

Responsibilities of the Recreation Consultant or Director

The recreation service manual is prepared by the recreation director or recreation consultant. It includes brief descriptive statements about all facets of the recreation service, including personnel, program, activities, administration and organization, methods, diagnostic and evaluative tools, and general guides to programming. This documents and facilitates general supervision of the recreation program by administrative personnel as well as coordination among all members of the deaf-blind service team.

Since recreation is one of the most recent considerations in the provision of services for deaf-blind, research on activities, methods, and programs as well as demonstration projects are imperative. Provision for research, evaluation, and demonstration is a basic part of the duties of the recreation consultant or recreation director.

Training in recreation activity or program is another important part of the work of the recreation consultant or recreation director. Those who will need training in the role of recreation activities and methods include professional staff, teachers, aides, parents, administrators, volunteers, and community service personnel. Time required for research and evaluation (see previous paragraph) and training can be up to one-third of the recreation consultant's or director's total schedule.

One means of overseeing the development of the professional recreation service is the preparation and dissemination of an annual report that covers general administrative and programming developments and in particular cites the specific contributions made to individual students and groups of students in terms of rehabilitation, education, and functional development.

The Future of Recreation for Deaf-Blind

We believe that recreational and cultural fulfillment for the deaf-blind will receive increasing attention from all who are concerned with deaf-blind persons. Education and employment are at best only partial answers to the total rehabilitation aspiration that we have for people who are deaf-blind. Thus, there are and will be voids unless a meaningful activity is provided to fill these voids. Recreation and cultural activities actually have the potential to be as meaningful or more meaningful than educational and vocational activities.

Recreation can, does, and will contribute to the education and rehabilitation of the person who is deaf-blind. Increasingly, personnel responsible for services to the deaf-blind will recognize this. On the basis of these points, we believe that recreation has achieved an initial level of credibility.

A major feature of the development of the recreation service for deaf-blind is the professionalization that is taking place. Let us assume that professionalization consists of general acceptance of a particular area, specific knowledge, research, professional education, registration or certification, personnel standards, recruitment, and professional organization. We are not suggesting the development of a new professional group, such as rehabilitation counselors. What we are suggesting is that to a limited but still very important extent, professionalization of recreation service for deaf-blind has occurred. Professional recreation service for the deaf-blind is just beginning, so growth can be anticipated. We believe that professional recreation service for the deaf-blind is an area that will receive increasing attention over the next five to seven years. This means that the future organization and delivery of service will be significantly improved to the benefit of the person who is deaf-blind.

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Alternative Living Programs

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A full ten years have passed since the onset of the rubella epidemic which brought the total count of deaf-blind children in the United States to an estimated five to seven thousand. The count as of January 9, 1975, according to the register in the U.S. Bureau of Education for the Handicapped, was 4,935. This number is expected to increase as further investigation occurs. The vast majority of these deaf-blind children are victims of rubella although other causes contribute.

Perhaps no comparably-sized group of handicapped children in modern history has presented a more frustrating challenge to parents and educators. And perhaps no other group of comparable size has had lavished upon it more professional attention and resources than has this group of deaf-blind children. Those of us who have worked with these children recognize the depth of the need for this professional attention and the vast amount of resources required if we are to salvage, in the name of human dignity, the potentials that lie trapped behind the combination of deafness and blindness and, often, a variety of other serious handicapping conditions.

At the present time the majority of these children are from nine to eleven years old. These children are approaching adolescence and will be entering the adult world in a few years. Programs developed to meet their needs as children may no longer be appropriate.

Planning programs for these children as adolescents and adults becomes a matter of increasing urgency. Alternative models must be identified and developed promptly.

Characteristics of the Children

No validated intellectual functioning scales can justly compare deaf-blind children with other

children who do not have the sensory handicaps of deafness and blindness. The nearest this author could come to a functioning criterion for deaf-blind children was a classification provided by Milton D. Graham (1968). Graham gives the following classification in terms of intellectual quotients:

90-110	Average
76-90	Slow learner
50-75	Mentally retarded
25-50	Severely retarded
0-25	Completely untestable

In applying the Graham classification to deaf-blind children, the author took IQ 50 as the dividing line between the trainable and educable and divided each into three segments. On the basis of this method, approximately 60 percent to 75 percent of these deaf-blind children appear to be severely mentally retarded. Another 15 percent to 25 percent appear to fall within the range of high trainable to low educable, and perhaps no more than 5 percent to 15 percent fall above the average level of intelligence (Smith, 1974). This scale of functioning levels is both arbitrary and crude. Data are still too incomplete for greater exactness, but no evidence has come forth during the past ten years to challenge these broad estimates.

Perhaps of equal importance are other behavior characteristics prevalent among these children. Hyperactivity, extreme distractibility, emotional dysfunction, and specific learning disabilities are commonly present in addition to the combined visual and auditory impairment.

Models for the Care of Deaf-Blind Children

Anyone familiar with the demands and behavior patterns of these children can understand the great

pressures that can be placed upon the family. Because the needs of these children are so great, many families do not have the physical or psychological resources to meet them. Thus, the care of deaf-blind children is shared in various ways.

The Family

In many, many cases the family of a deaf-blind child has either collapsed or has been forced to release the child from the home in order to function. Most families make a superhuman effort before giving up; yet, more than half of the families of these severely handicapped children have been unable to endure the presence of their child in the home for any significant period of time. In many cases, for the sake of other family members, the best solution is that the severely handicapped deaf-blind child not be a constant family member.

Among those families who have been able to function satisfactorily with a deaf-blind child, a considerable number have been able to do so because the child is in a residential educational during vacation periods, or during the summer. In many cases, this respite from the daily and constant task of adapting the family to the demands of the severely handicapped deaf-blind child has made it possible for the family to survive while still retaining the child as an active family member.

Although the group is comparatively small, some families have found the resources within themselves to adapt to the needs of a severely handicapped child. However, a local day class or a residential class placement is always a tremendous assistance to family stability. Support of the family has become recognized as one of the most impor-

Table 1
Distribution of Children Reported by
Regional Centers for Services to Deaf-Blind Children

Regional center	Number of children						
	On register	Residential schools	Day classes	Custodial institutions	Custodial institutions, VI-C support	Supported by natural families	Foster and nursing homes
Mid-Atlantic/ Caribbean	811	230	220	272	N/A	365	44
Mid-West	598	76	83	61	N/A	159	7
Mountain Plains	320	197	84	94	94	113	5
New England	259	151	47	35	21	183	6
Northwest	311	112	N/A	74	64	112	31
South Atlantic	482	78	106	235	N/A	172	12
South Central	483	79	112	198	152	N/A	N/A
Southeast	416	76	97	118	45	244	20
Southwestern	648	75	250	323	83	231	98
Texas	450	18	157	220	50	210	20
Totals	4,778	1,092	1,156	1,630	509	1,789	243

tant priorities in planning for this population. An increasing amount of federal and state resources is for providing social services to both the natural family and foster family.

The Foster Home

One aid to the natural family of the deaf-blind child is foster home placement. This form of substitute family seems to have grown in popularity over the past ten years and has demonstrated some outstanding successes. Foster family placement has been used in several ways. First, it has served as a substitute for the natural family. On this basis, the foster family is subject to similar pressures that often break apart the natural family. As a result, for a deaf-blind child to find himself or herself placed in several different foster homes is not uncommon. Only a well-organized and dedicated foster family can hope to endure the behavior patterns of some severely handicapped deaf-blind children for a long period of time. Strong, well-disciplined foster homes are not easy to find in large numbers. Therefore, the number of foster home placements substituting for the natural family continues to be a small one.

The foster home is also used in conjunction with the natural home. Under this plan, a deaf-blind child is temporarily placed in a foster home. The natural family and the foster family share responsibility for the home-rearing of the child and thereby make the situation workable for both. Again, limitations are involved in the recruitment of strong, well-organized, and willing foster families.

A variation in foster home placement arises when relatives of the natural parents provide a home setting for these children either on a part-time or a full-time basis. Placements of this kind are sometimes very effective; however, they may not be satisfactory for long-term placement, particularly when aging grandparents are involved.

Similar in strengths and weaknesses to the traditional foster home is the nursing home, which in some areas has been used to care for deaf-blind children.

Another foster home setting is the professional foster home, which is a home in which the parents are paid professionals who have been trained to handle these children. These professional parents are prepared to reinforce the educational process of either the day class or the residential school with a consistency that will advance the learning and growth of the child in a positive way. This is a setting that gives considerable promise but which is rather expensive to develop and, as yet, has

received only token application. In the years ahead we would do well to exploit the potential of professional parents in homes of this kind both for the severely handicapped children of future generations and for deaf-blind adults who with assistance may be independent, contributing members of society.

Custodial Institution Placement

Perhaps the bleakest of the care models involves the number of deaf-blind children in custodial institutions. Available figures indicate that at least half of the deaf-blind children are placed in this situation. When more complete figures become available within the next two or three years, the percent may prove to be significantly greater. The large number of custodial placements carries with it several interesting implications.

First of all, large numbers of deaf-blind children have been deemed to be severely mentally retarded and to possess extremely limited potential. Certainly, a good amount of truth is reflected in this estimate; many of these custodial children are extremely limited in mental functions and physical functions. In the second place, a large number of parents and families have experienced great difficulty in attempting to cope with a deaf-blind child. It is easy to understand how a family can turn to custodial placement when it has a child who fails to respond normally, either through hearing or vision, and who demands the total energy and resources of the family rather than just his or her fair share.

The situation may also indicate the inadequate availability of diagnostic processes to determine effectively the true potential of these children. Six to ten years ago, when most of these custodial placements were made, even the most sophisticated diagnostician had difficulty penetrating the results of deafness and blindness to measure the potential of the child. In those days only a few diagnosticians had sufficient experience with these children to possess any degree of skill in this respect.

Finally, this large number of custodial placements indicates the lack of adequate alternative programs that would be more in keeping with the true needs of these children. Here again, of course, progress is being made under the provisions of Title VI-C, Education for the Handicapped Act.

Statistics Relating to Present Settings

In preparing this paper, this writer communicated with the ten regional center coordinators for services to deaf-blind children to gather the most

recent statistics related to present programs for deaf-blind children. In every case, the regional coordinators were most cooperative in examining their records and providing the requested figures.

The total number of children reported by the regional centers exceeds the number of children registered with the Bureau of Education for the Handicapped. One reason for this may be that some of the questions were subject to different interpretation by the respondents. In the case of family involvement, for example, different criteria may have been used for judging when a family is involved with the child. In the case of foster home placements the figures may represent duplicated counts. A number of children may be placed in foster homes during the school year and spend vacations and holidays at home with the natural families. However, as a reflector of trends and programming status within the deaf-blind population, these figures can be viewed with a high degree of dependability. Certainly as a basis of planning for the future they offer excellent guidelines.

Information thus far seems to present a rather gloomy picture of our population of deaf-blind children. The picture is one of high incidence of severe handicapping conditions, including mental retardation; it suggests a sharp limitation of potential; it reveals a wide swath of family devastation; and it implies an inadequacy of appropriate facilities and resources for fully discharging our responsibilities to these children.

Educational and Training Programs

Over the past six years, deaf-blind children in large and ever increasing numbers have found their way into a variety of educational programs, thanks in large part to Title VI-C of the Elementary and Secondary Education Act and a sympathetic Congress, which has provided necessary supplementary funds. Progress reports on children in these various programs, in which trained and knowledgeable personnel are bringing to bear an educational structure reinforced by adequate materials and equipment, reveal steady achievement on the part of almost all children. This is not to suggest that all of these children can become self-sufficient, normally functioning adults. It does indicate, however that given a carefully structured, adequately staffed, and properly supplied program, deaf-blind children can make progress toward obtainable goals within the framework of their individual potential.

Among the children in the upper ranges of ability, we find children learning to communicate through fingerspelling, signing, and speech. These

same children are demonstrating advanced skills in independent daily living, including mobility within safe environmental limits. At the middle ranges of measured ability, children in these programs are acquiring some communication skills and are demonstrating that they are able to acquire a number of independent daily living skills. For children with a low level of potential, for whom programs have been established in custodial institutions or have been established in community residential settings, marked gains have been noted.

Before the children were exposed to training, they were considered to be entirely dependent on others. Under stimulating programs many have been trained to feed themselves, clothe themselves, move about by themselves, and perform a variety of simple tasks. In many cases, with adequate programming, hyperactivity has been reduced and replaced with purposeful and meaningful activities. If it is the goal of our society to provide every one of its citizens, regardless of potential, with an educational program designed to realize fullest ability, then the case for continued and even more extensive educational programs for our deaf-blind children is a strong one indeed.

Models for the Future Care of Our Deaf-Blind in Adulthood

The largest number of our deaf-blind children today, those resulting from the rubella epidemic, are between nine and eleven years of age. Within the next ten years they will be adults. Hopefully, a large number of them will be in a position to return some of society's investment in them by making a contribution to their own independent living.

Let us explore some of the areas where adult services will be necessary and examine some of the models that may be applicable. This is of extreme importance because if we are not ready for our deaf-blind children when they become adults, we will have squandered much of the investment we have placed in them as children.

Vocational Training

Let us look first at some of the future vocational prospects and needs of this population. We can reasonably expect that the many children who are now in continuing educational programs, as well as those who are added to programs within the next ten years, will receive, in addition to training in communication skills, training in independent living, concept development, and prevocational skills.

This means that by the time they are adults they will be ready for or have need of specific vocational training programs and vocational placement programs.

If it is true that over 60 percent of this deaf-blind population falls within the trainable level of intellectual functioning, then this group of handicapped people as adults will require particular kinds of vocational programming (Smith, 1974). For a large number a sheltered-workshop type of activity will be required, stressing simple, repetitive manual skills. For others even a sheltered workshop will be insufficiently structured. The answer for these people may be some type of home industry based in their place of residence. A number of others, of course, will have as their major vocational contribution the acquisition of satisfactory self-care skills so that they may reduce their degree of dependency upon others.

The potential of another sizable group, perhaps as much as 25 percent of the total, lies above the trainable level. For this group vocational expectations will be at a higher level. Some children in strong educational programs around the country are already beginning to demonstrate this more advanced vocational potential. We must be ready with a vigorous vocational training and placement service. This service must include a thorough investigation into job feasibility within industry for these handicapped persons. We may be pleasantly surprised by the high degree of skill many in this group can achieve once they are given adequate preparation.

Finally, we come to that rather small group of deaf-blind, perhaps no more than 5 percent, with superior intelligence, high interest, and advanced maturity. In some respects this is the most difficult group of all with which to deal in terms of vocational objectives. Their intelligence plus their potential for college training can qualify them for a variety of professional jobs. Many professional positions depend so vitally upon fluent communication with individuals and with groups that the superior deaf-blind person, in spite of his or her education and skill, is at a serious disadvantage. Usually the deaf-blind person, if he or she is to succeed professionally, must have a seeing and hearing companion to expedite communication with others and to assist in travel. Not too many professional positions can support the additional cost. If the deaf-blind person has sufficient useful vision to travel independently and to deal with other aspects of the group communication process visually, then his or her chances for success

professionally are enhanced. On the other hand, many of those who are superior and who have no hearing or vision might be better advised to seek vocational outlets in the higher branches of manual skills. Nevertheless, we should undertake innovative thinking and careful investigation to uncover professional areas in which this small group of superior deaf-blind persons may succeed. Under the right conditions and with proper training, they can make significant contributions to our social order.

Housing

Next, let us consider the living accommodations that these deaf-blind children will require as adults some ten years hence. The great majority of them will require some form of assisted living arrangements. Most will have acquired self-care skills, and many of them will have acquired many independent living skills, but their inability to travel alone and to communicate easily and freely with strangers will place sharp limits on their independent living. True, a number who have useful travel vision and sufficient intelligence to exercise good judgment can achieve complete independence, but these are likely to be a minority of the total population. A variety of assisted living models, therefore, needs to be examined.

The natural family. The natural family, of course, is the first and in many cases one of the most effective and desirable models to be considered. If the natural family has survived the presence of a deaf-blind member through childhood into adulthood, the chances are that its bonds are strong enough to carry the deaf-blind member through continued adulthood. Fortunately, some of our present deaf-blind children will find this kind of support when they become adults. However, in the nature of things, not many first generation members of the family survive as long as the handicapped member of the second generation may require their assistance. Furthermore, not all natural families may be located where vocational opportunities exist for the deaf-blind member nor be in a position to relocate accordingly. In addition, a large number of the families of these children are unable to function significantly in giving assistance to them. Obviously, additional living models will be required.

The foster family. The foster home or foster family model of assisted living for some deaf-blind adults should hold considerable promise for the future and should be exploited. Foster homes have been very useful with deaf-blind children. They

give the children the opportunity to escape the custodial institution and to be enrolled in meaningful educational programs. However, our experience with foster homes has been rather short. Deaf-blind children often experience two or more foster homes during the period of their childhood. It is not necessarily an unsatisfactory situation for a deaf-blind adult to have spent part of his or her childhood in more than one foster family placement. Undoubtedly, a great amount of groundwork will need to be done if the foster family model is to become a satisfactory one for any large number of deaf-blind adults. We do not know how responsive a foster home might be when faced with the responsibility of accepting a deaf-blind adult for a long-range program. Nevertheless, the model is well worth exploring, for it may answer the needs of many deaf-blind adults. The security and comfort to be provided the deaf-blind adult by a good foster family is next best to that provided by a positive acting natural family.

Foster homes should be sought in residential areas adjacent to industrial and business centers where vocational opportunities may be found for deaf-blind adults or where sheltered workshops exist. One of the key components of successful foster family placement, as well as natural family placement, is the regular employment of the deaf-blind family member. If possible, the foster home should be located where religious, social, and other group organizations exist and are willing to accept deaf-blind persons among them and to make the necessary adaptations in their routines to provide the handicapped individual with recreational and other social activities.

The group community residence. Let us consider next a model for living that may be effective for a larger number of deaf-blind adults than those models already considered. This is the group community residence. For a number of years now, as part of a general deinstitutionalizing process, group community residences have been springing up around the country to provide assisted living situations to trainable retarded adults; to emotionally distressed or mentally ill adults recovering from treatment; and for retarded, disturbed, or homeless children. As a rule, these residences house from eight to twelve clients under the supervision of competent, paid professional house-parents, often young couples. Client members maintain themselves and the house, prepare the meals, budget and purchase food and supplies, and perform housekeeping chores. Usually, one of the chief requirements for client membership in the resi-

dence is vocational employment, either in open industry or business or in a sheltered workshop or day activity center. It is conceivable, for the more severely retarded, that vocational activities centered in the home might be possible, although it may not always be desirable. Requirements for the location of a group residence include nearness to employment opportunities, the presence of medical and health services in the neighborhood, the proximity to reasonable public transportation, the presence of social and recreational outlets, and a posture of acceptance on the part of the citizens of the community.

After the initial investment required for the purchase of a suitable house, these residences can be almost self-supporting if they are operated properly. Each client, either from earnings, supplementary security income, or a combination of these, is expected to pay approximately \$40 a week toward his or her share of the operation. This fund takes care of the food budget and the maintenance of the residence and can meet a share of the salaries of the professional houseparents, particularly when the house is owned outright. In many cases houses are rented or leased. If so, additional funds must be available either from government funding sources or from private donations. At any rate, this investment in real estate is small compared to the human values to be realized from these residences. A number of models for community residences are available and should be examined carefully as an alternative living situation for our deaf-blind adults. A number of these residences for severely handicapped persons are operating throughout the Commonwealth of Massachusetts. Two of them have included blind retarded members and are prepared to accept deaf-blind clients. They are: Massachusetts Residential Program, Inc., 129 Mt. Auburn St., Cambridge, MA 02134; and The Step, Inc., 80 Mt. Auburn St., Watertown, MA 02172.

Ideally, an individual deaf-blind adult would be placed in a residence housing adults with other handicaps. We would then have an integrated community residence that could bring additional social advantages to our deaf-blind adults without imposing too great a burden upon the other members of the residence. If careful preparation is made, an integrated plan of this kind could be successful. In many other cases, however, an integrated plan of this kind would not be practical for one very good reason: Our deaf-blind adults, except for the relatively few who may master speech, will depend upon manual communication

techniques. This form of communication will not be understood by the seeing members of the residence until a training program has been undertaken to prepare them. Furthermore, before a training program in manual communication can be undertaken, the other clients in the residence must be willing to learn.

Although an integrated community residence may be the ideal, the nonintegrated community residence may be the most practical one for the greatest number of deaf-blind adults. In this nonintegrated model, eight to twelve deaf-blind adults can be brought together under the direction of professional houseparents. If we have done our preparation properly while they are still children, they will be able to care for themselves independently in a home setting. They should be able to assist with household chores and cooking responsibilities. They should have vocational training that will enable them to be employed. They should have developed sufficient social awareness and expertise to associate with other people at least to the extent their method of communication will allow. Certainly, right now is the time we should be giving attention to this preparation of our deaf-blind children.

Special attention must be given to several factors in these community residences. First, the houseparents must be selected with particular care. They must be in tune with the special problems and needs of deaf-blind persons and above all must be thoroughly prepared in their residents' special means of communication. Second, in the selection of the deaf-blind clients, attention should be given to including some who have useful vision along with those who may be totally blind. Particular attention must be given to modes of transportation within the community because those clients who do not have travel vision must follow uncomplicated routes if they are to travel alone. A strong effort must be made to enlist the goodwill of the citizens of the community in terms of accepting these multihandicapped people. A program should be developed to recruit volunteers to assist these deaf-blind persons as they go into the community for shopping, recreational, and social experiences. This community residence model is probably most appropriate for deaf-blind adults ranging in potential from the upper-trainable to the middle-educable levels. With modifications in expectations or goals for the clients, however, it could apply to those at either lower or higher levels. Certainly, many will be able to prosper in this form of community residence.

Custodial or total-care institutions. Finally, let us examine the custodial institution as a setting for some of our deaf-blind clients. Every state has at least one of these residential institutions; many states have several. Through the years large numbers of children and adults have been institutionalized because of their severe mental retardation or other incapacitating handicaps which, according to popular belief, rendered them unfit to maintain themselves or to be maintained in open society. In recent years deinstitutionalizing programs have served to reduce the size of these custodial institutions by placing large numbers of retarded and otherwise handicapped persons in community-based settings. In many cases this movement is appropriate. Certainly, large numbers of custodial clients can, through proper training and guidance, make a contribution outside the institution.

On the other hand, for that rather large segment of our severely retarded deaf-blind population ranging from the middle-trainable downward, perhaps the custodial institution with important modifications can be the most successful model for supervised living. Unfortunately, the term custodial institution still conjures up images of unclean, undermanned, unsanitary, and backward facilities in which large numbers of severely handicapped persons are neglected or even abused in a most inhumane fashion. Yet, under enlightened administration and adequate funding, these conditions might well be replaced with modern effective living units in which the severely handicapped person can be provided with a pleasant, comfortable living environment and rehabilitation program designed to develop his or her full potential. The Walter E. Fernald State School near Boston, Massachusetts, has converted a small staff residence into a training cottage in which some of its clients receive instruction in independent daily living skills. Furthermore, on the Fernald campus, ground has been broken for a series of family-type cottage units in which independent daily living skills can be provided to prepare clients for entry into local communities. These units will be completed when additional state funding is provided. Lincoln State School in Lincoln, Illinois, has also turned staff residences into model training houses for independent daily living skills.

Is there any reason why some of the features of the community residence described here could not be applied to the campus of the custodial institution? Could not small family units with professional houseparents be established in cottages housing no more than 12 clients? With such a

program our severely retarded deaf-blind adults could continue to receive training and supervision in their daily living skills and could participate as much as they are able in the maintenance of their home. Workshop facilities could be expanded on the campus of the institution to include vocational training and employment opportunities for those individuals able to profit from them. Introduction into surrounding local communities for social and recreational purposes could be made when the deaf-blind clients are ready and the local citizens are willing to accept these persons. Integration with other adults who are not deaf-blind and who are at similar functioning levels would also be a possibility.

The best argument of all for establishing this type of facility is the fact that the custodial institution is where a large number of our deaf-blind children are. For those who do not demonstrate the potential to reach higher levels of living skills entitling them to more sophisticated settings in local communities, the campus of the custodial institution seems to offer the most effective setting for providing an enlightened life-style during their entire careers. Under the enlightened living and training program in the institution suggested here, perhaps more of these severely retarded deaf-blind children will be able to develop the skills necessary to live as adults in some type of supervised dwelling in society. Certainly the institutional program should be so structured that it will allow any deaf-blind person who reaches the necessary levels of competence to move into the community.

Summary

We have considered a number of possible living settings for our deaf-blind children when they become adults. We have discussed the natural home; the foster home; the community residence, both integrated and nonintegrated; and the custodial institution. Some of these models are better for certain types of our population than others, but certainly all models will be needed to meet the demands of this population within the next ten years. One or two additional factors would seem to emerge from the foregoing discussion. First of all, great flexibility within each of the living settings is imperative. The living setting itself and associated areas of life experience, including employment, social and recreational activity, and degree of independence in living, must be open. Provisions must be made for movement by any individual from one setting to another as his or her capabilities and interests change. This is particularly true

at the custodial level, for no one can tell how far some of the children we consider to be severely retarded may go with proper training and encouragement. Secondly, in the next ten years we must attend to careful planning and harnessing of resources to be ready for these deaf-blind persons when they are ready to assume their place in society as adults. Let us now turn our attention for a time to this planning process and to some of the agencies that must assume a role of responsibility in it.

Programs Serving the Deaf-Blind

Programs are readily identified by those who are familiar with services for deaf-blind persons. At the federal level are the National Center for Deaf-Blind Youths and Adults and the Regional Centers for Services to Deaf-Blind Children. At the state level are the various state commissions for the blind and rehabilitation commissions for the handicapped and the state departments for special education. In a few states other governmental departments may be charged with the responsibility for deaf-blind persons. At both state and local levels are also a variety of private agencies that include programs for deaf-blind persons. A growing trend throughout the country is for state education agencies to delegate responsibility for directing programs to local boards of education.

Here, then, is a rather imposing array of program personnel and financial resources all committed to the responsibility of promoting the education or the rehabilitation of deaf-blind persons from infancy through adulthood. Obviously, the first and most overriding need is for a plan of cooperation among these various agencies so that they may share both the responsibility and the resources for the best interests of the deaf-blind without wasteful overlapping or conflict. Perhaps the first step in considering a plan of cooperation is to identify both the role and the sphere of responsibility attached to the various types of programs.

Role of Local Government Agencies

In our present social order, the primary role and responsibility for both the education of deaf-blind children and the rehabilitation of deaf-blind adults rests squarely upon the shoulders of state and local governmental agencies. These agencies have been mandated by law to provide the deaf-blind clients in their respective geographical areas with adequate services. Any plan of cooperation must take this primary responsibility of state and local governmental agencies into account and consider the role

of other agencies as supporting and augmenting. In many parts of the country, these state and local governmental agencies have been slow to recognize the rapidly increasing need for services for deaf-blind children and adults and the great financial investment required to provide these services adequately. The financial cost of adequate programming continues to stagger local officials, and to expect that local and state resources can carry the total cost is unrealistic. On the other hand, awareness of the extent and nature of the problem and willingness to take action is growing at the local level. State departments of education are helping to finance local programs for deaf-blind children and are supporting teacher training programs. State rehabilitation commissions and commissions for the blind and for the deaf are beginning to understand the needs of deaf-blind youths and adults and are beginning to explore ways and means of providing practical rehabilitation services for them. All possible means should be taken to expand state and local activity for that is where the primary responsibility must lie and where the basic service plans must originate.

National and Regional Centers

The two federal programs that serve deaf-blind persons are the National Center for Deaf-Blind Youths and Adults and the Regional Centers for Services to Deaf-Blind Children. These federal programs carry a strong mandate to support and to cooperate with both governmental and private local agencies serving the deaf-blind. They are designed to assist in local programming, but in no way is the intent that these federal programs will assume the primary responsibility for serving deaf-blind persons throughout the country. Since these federal programs were created for the sole purpose of serving the deaf-blind, they have been significantly ahead of many local agencies in acquiring knowledgeable staffs and an expertise for developing effective programs. They can provide extremely valuable assistance to local agencies that are trying to initiate effective programs for their deaf-blind clients. In the case of the National Center for Deaf-Blind Youths and Adults, assistance at present must be limited to expert consultation and guidance and to the development of a model rehabilitation center for deaf-blind adults. The national center is used to demonstrate to local agencies throughout the country the components of effective rehabilitation services, including training of personnel. The original model training center is in Long Island, New York. Within this past year

the national center has established a satellite demonstration training model at the Arkansas Enterprises in Little Rock, Arkansas. Another satellite training model program is being planned for California. These satellite programs should extend considerably the effectiveness of the national center in bringing support and assistance to state and local agencies throughout the country. Let us hope that in the future Congress will augment the budget of the national center so that the center may provide some financial support to local programs in addition to its present consultation and guidance function.

The Regional Centers for Services to Deaf-Blind Children have been extremely helpful in assisting local educational agencies to establish effective programs. The regional centers have been provided by Congress with funds to provide some financial assistance for local programming. Here again, because of the great expense involved in providing an adequate education for deaf-blind children and because of the overwhelming financial pressures faced by local and state agencies, let us hope that Congress will increase the federal share of the finances needed to support these educational programs. This will be necessary if every deaf-blind child is to receive the kind of a program he or she should have.

One further topic related to the two federal programs merits discussion. The deaf-blind rubella children are growing into adolescence and into that age at which prevocational and vocational training become primary objectives in preparing them for adulthood. We have a considerable number of adolescent deaf-blind youths between the ages of sixteen and twenty-one years. As time passes, the function of the national center and the regional center will tend to merge, and an overlapping of responsibility and perhaps of services could occur. Toward avoidance of wasteful duplication and possible conflict, the two programs must be operated in a cooperative manner, and their roles must be clearly defined. An advisory council to the National Center for Deaf-Blind Youths and Adults is already functioning with regular meetings and includes key personnel from the Regional Centers for Deaf-Blind Children. However, further review of the relationship between the two programs would be in order.

The regional centers have funds not only to provide expert counseling and guidance to local agencies, but also to provide direct financial assistance to local educational programs for deaf-blind children. Perhaps as these children now being

served locally grow into adulthood, the regional centers should use some of their funds to assist local rehabilitation agencies in providing advanced vocational training and placement and to support community residences and other forms of living settings. Certainly, the regional center staffs will have the expertise to promote vocational training programs. State and local rehabilitation agencies are going to require both expert counsel and guidance and some financial assistance to provide adequately for the many deaf-blind adults who will need their services.

Some persons argue that as the deaf-blind children become adults, federal responsibility for them should be transferred to the national center and that gradually regional centers would be phased out as their services are no longer needed by these children. To phase out the regional centers could mean the loss of trained, experienced personnel who understand local needs and who could be very useful in advancing local programs for adults. It could also mean the loss of significant federal funds to support local programs unless Congress can be persuaded to expand the budget of the national center and encourage it to assist in local funding. Furthermore, we are likely to have a continuing flow of deaf-blind children, perhaps not in the large numbers resulting from the rubella epidemic but in sufficient numbers to require continuing the services of the regional centers. Some form of merger between the national center and the regional centers would seem appropriate. However, such a merger should not destroy regional center staffs that are working effectively at the local level and that will continue to be needed to support local agencies with expert guidance and supplementary funds. Perhaps a merger of these two programs at the federal level may be desirable with one official responsible for directing the services of both. Or perhaps the programs should remain separate but subject to the decision-making authority of a small council representing both. Regardless of the form such a merger would take, cooperation between these two programs is needed if we are to have an effective service for deaf-blind persons in this country.

In the meantime, both federal programs are faced with one extremely important problem upon which

prompt and continuing cooperation must take place. This is the problem of providing adequate prevocational and vocational training programs and training in independent daily living skills for adolescent deaf-blind children. This writer believes that we need several residential rehabilitation training centers established around the country. Where but in a group residential setting that is staffed by professionals can numbers of our deaf-blind youths be introduced effectively to the necessary skills of independent living? Where but in this same kind of residential setting with a good deal of individual attention can these same deaf-blind youths be provided with adequate vocational training? Youths favored with a very effective family will acquire the necessary skills at home, and others may be able to acquire adequate vocational training skills in a program for less handicapped persons, but these are likely to be the exception rather than the rule. We already have a number of residential settings staffed by professionals with considerable knowledge of these training processes for deaf-blind young people and with plenty of potential for expansion if nourished in the proper fashion. Among these are residential schools both for the deaf and for the blind which should be exploited fully. We already have one or two successful models available to demonstrate how effective rehabilitation services can be provided for deaf-blind youths when desire and resources are brought together (Perkins School for the Blind, Community Residence Training Program for Deaf-Blind Adolescents, 175 N. Beacon St., Watertown, MA 02172). Let us move forward, then, in a full spirit of cooperation to prepare ourselves to meet the needs of deaf-blind adolescents.

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Training of Personnel

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Historically, two major professions have offered programs and services to deaf-blind persons: teaching and social work. Social workers, assigned deaf-blind persons as part of a total case load, normally dealt with *adults*, while teachers usually worked with school-age *children*. Yet, few personnel of any kind were specifically prepared to work with deaf-blind persons of any age. Since the ultimate factor for determining life-time placement of deaf-blind persons often is their rate of progress through various training programs, it is essential that (1) these programs be designed to meet their needs; and (2) these programs be staffed with well-trained personnel.

Preparation Programs

Prior to the 1963-65 rubella epidemic, formal preparation for work with deaf-blind children was provided to classroom teachers only. Only the program at Perkins School for the Blind, in conjunction with local institutions of higher education, offered a degree program for teachers of the deaf-blind. Teachers trained in the Perkins program were hired by seven residential schools for the blind across the country. The population was usually educable, and the children were integrated as quickly as possible into classes with the blind population of the school. For the most part, the children were placed in dormitory settings with their blind peers, and personnel trained specifically to work with the deaf-blind were not required in other than the academic classroom settings. With a total school population of less than 100 children, personnel needs were not great in terms of total numbers. Nevertheless, teachers with formal preparation were insufficient to meet the demands (Dinsmore, 1966; Wagner, 1966; and Conference

of Educators of Deaf-Blind Children [Watertown, Mass., Perkins School for the Blind, 1954]). The majority of teachers of the deaf-blind were taken from other fields and given inservice training to make them knowledgeable and competent in the teaching of the deaf-blind.

A major change in the status of teacher training and educational programs for the deaf-blind came about when the United States Office of Education (USOE), Bureau of Education for the Handicapped (BEH), funded four training programs in 1967 to train professional teaching personnel. These programs were conducted at (1) Boston College, as part of a cooperative training program with Perkins School for the Blind; (2) George Peabody College for Teachers, where a program was funded to train teachers of the multihandicapped, including the deaf-blind; (3) Michigan State University, where a five-year program was developed with dual emphasis on training teachers for blind as well as for deaf-blind students; and (4) San Francisco State College (now San Francisco State University), where a program was to be developed through the cooperation of faculty then training teachers for the visually and/or hearing handicapped. Later, programs at Portland State University and the University of Texas were funded through the same funding source to prepare teachers for deaf-blind children.

In 1971 a conference was held to discuss the needs for professional preparation in the field of service to the deaf-blind. This conference was attended by representatives from all ten regional centers, from the six colleges and universities then engaged in teacher preparation, and from the USOE (BEH).

The concerns of those attending the conference were reflected in their recommendations. Many of the graduates preparing to teach severely handicapped deaf-blind children had been prepared in traditional techniques for use with the deaf-blind. These techniques had proven successful with the educable deaf-blind population. However, the children being identified by the regional coordinators were, for the most part, not educable. Those persons involved in teacher preparation expressed a desire to be more attuned to the needs of this population but lacked funds to visit programs or to place and supervise students. Thus, recommendations were made in an effort to meet what were considered serious shortcomings in the preparation of personnel to meet the needs of the entire deaf-blind population.

One of the suggestions from that 1971 conference, that federal monies be used to expand the training programs for personnel in the area of deaf-blind, has been effectively implemented. Since the 1971 meeting, a preparation program at California State University, Los Angeles, has been funded through USOE (BEH), and the University of Pittsburgh has begun a program to prepare early childhood education teachers to work with the severely handicapped, including the deaf-blind. Other programs such as those at the University of Washington and Teachers' College at Columbia also offer courses in working with the deaf-blind.

In her analysis of the status of special education in the colleges (1974), Josephine Taylor states:

During the 1972-73 academic year, seven colleges and universities graduated one doctorate, one educational specialist, thirty-six master's, and eight bachelor's degree teachers plus twelve certification only teachers of deaf-blind children. The number enrolled in preparation programs for the deaf-blind during the current year includes six doctoral students, one educational specialist, one hundred and eighteen master's, ten bachelor's, and forty certification only students. This should not be interpreted to mean that there will be a gigantic increase in the number of graduates this year, as some programs are more than a year in length and the number also includes part-time students who may require several years to graduate. It seems probable, however, that the number who graduate will be at least double that of last year.

In general, there is a trend toward competency-based education as well as an attempt to promote meaningful teaching strategies at the college level. Programs are becoming concerned with more severely handicapped children, and students in training are being exposed to the wide range of

handicapping conditions with which deaf-blind children may be afflicted. The emphasis on commonalities that exist between areas of special education for the handicapped varies within the different programs. Some emphasize one type of exceptionality more than others. Some deal only with the needs of deaf-blind children, while other programs consider the broad range of handicapping conditions.

The variety of teaching techniques also varies between programs. The practicum base is becoming broader, but much of it depends upon the interests and desires of individual students as well as on the physical or geographical location of the preparation program. This means that not all students receive an equally broad education. There is an attempt, however, to provide a variety of practicum experiences so that students will be exposed to many different types of situations.

The use of USOE(BEH) special project funding for programs that might not meet the traditional criteria, but will, hopefully, lead to new methods and techniques in personnel preparation, has been especially effective in trying innovative techniques to prepare personnel in the area of the deaf-blind. Special projects are designed to be developed and implemented over an initial planning year, with three additional years of operation.

One of the first USOE(BEH) special projects was awarded to George Peabody College for Teachers to investigate team teaching as a means of preparing personnel to work with multihandicapped children, including the deaf-blind. Techniques for working with both the children and their parents were investigated.

Perkins School for the Blind is currently involved in a special project in which university students from various regions are brought in and trained during the summer. The students then either go back to their respective colleges to continue their regular studies or take positions in the field of service to the deaf-blind even though they have not been academically prepared in a college that offers a major in that area.

The National Recreation Program at the University of Iowa is a special project designed to train personnel to work with deaf-blind persons in the area of therapeutic recreation services.

Elementary and Secondary Education Act, Title VI-C, funds have been used for a National Leadership Training Institute for professional workers in deaf-blind programs. Established at California State University, Northridge, the institute is a two-summer college training program, with additional work required during the year in supervised field

work. This program offers a master's degree in administration and supervision. The program, just completing its first year, is the first national attempt to develop administrators for deaf-blind programs (*National Advocate for Deaf-Blind Children*, 1974). Many junior colleges and community colleges across the country are training paraprofessionals and using many of the deaf-blind programs as practicum facilities. These programs, in turn, are a source of employment for the newly-trained paraprofessionals.

Inservice Training

Because few students are prepared in deaf-blind training programs at colleges and universities, and because large numbers of teachers are already in

the field without formal preparation in teaching deaf-blind children, increasing emphasis has been given to inservice training. Inservice training is used to acquaint teachers and professionals from other areas with the unique needs of deaf-blind children. A career-ladder approach to inservice programs has been suggested so that aides can progress to teachers and teachers to supervisors or administrators. Inservice training also provides ongoing program evaluation and development and should incorporate all program personnel, including bus drivers and administrators.

Contact was made with current deaf-blind regional offices to assess the extent of inservice training currently being offered. (See table.)

Table 1
Summary of Implemented Recommendations

Recommendations	Answer by region	
	Yes	No
Junior colleges/community colleges train paraprofessionals	3	7
Communication established between centers and university	10	—
Center coordinators recruit for the university	7	3
Career ladder developed in each region	1	9
Ongoing and self-evaluation	9	1
University deaf-blind personnel assist inservice training	8	2
All regional personnel be inservice trained	10	—
Regional committee develops inservice plan	7	3
Traveling resource team available	7	3
Formulate a registry of trained personnel	1	9
Research effective teaching techniques, and so forth	4	6
Additional institutes	2	8
Regions pay university directors to visit programs to identify needs in updating training programs	7	3
Regional supervision of practicum students	10	—
Train paraprofessionals formally	1	9
Develop a curriculum guide	2	8
Multiyear funding	10	—

All coordinators expressed a commitment to inservice training, and such training remains a top priority within the regions. The extent of personnel participation in inservice training differs between and within regions, and attendance criteria vary from one workshop to another. The format of the workshops is varied and includes lectures, participation, and demonstrations.

Short-term experiences ranging from a few hours to a few days have been utilized most often in inservice training, with programs geared to meet the specific needs of personnel currently working in the field. Other inservice training courses have taken place over a longer period of time, such as the summer workshop offered by the regional center located at the Michigan School for the Blind. John Tracy Clinic in Los Angeles has offered summer programs for teachers at the graduate level and also has had a short-term training program for preparing home guidance and training personnel to work with parents of children not receiving other services (*National Advocate for Deaf-Blind Children*, 1974).

State monies throughout the country have been made available for use in funding workshops, summer training programs, special courses, and grants covering tuition payment for those attending inservice programs. A great deal of regional money has been put into institutional programs as well because of the large numbers of deaf-blind children found in such settings. Many institutions have offered their staffs inservice training in which a multidisciplinary approach is emphasized. These inservice programs have included teachers, physical therapists, social workers, occupational therapists, ward workers, aides, and nursing staff. In some cases foster grandparents have been included in these inservice training programs. These foster grandparents have been an additional source of personnel available to deaf-blind children and have made a valuable contribution to many programs.

Regional deaf-blind center libraries containing films, videotapes, toys, instructional materials, and teaching supplies have been developed. The use of these libraries and materials has become a means of upgrading the skills and knowledge of those in the field and is another method of providing inservice training. Most of the regions are now publishing conference proceedings, and the number of publications that are available regarding the deaf-blind has increased accordingly. These publications have resulted from local and regional workshop efforts and are geared to different consumers.

Several regions have developed videotapes for teaching purposes. These tapes are available on loan to other regions for inservice training purposes. Newsletters published by various regions are also a means of providing inservice training. These newsletters help professionals in the field become aware of new publications that are available, names of specialists dealing with the deaf-blind around the country, and new techniques and programs that are being developed across the nation.

Other Types of Training

Because of the shortage of trained personnel and the recognition that parents are the child's first teachers, programs training parents to work with their deaf-blind children have received a great deal of emphasis. Training models have varied, but all have demonstrated that parents can efficiently teach their own children.

Some programs have been used in training both teachers and parents. These programs, some developed under the First Chance Network, USOE (BEH), have resulted in publications useful to parents, teachers, aides, counselors, and social workers. Other useful materials have been published by professionals working in allied fields. Many books written for retarded children, for example, have been very helpful to parents and teachers in getting deaf-blind children to walk, eat, and be toilet trained.

Allied fields have been particularly involved with multihandicapped deaf-blind children. Multidisciplinary personnel such as speech therapists, audiologists, occupational therapists, physical therapists, paraprofessionals, and child development specialists are being trained in currently operating programs for deaf-blind children. These programs have also become an observation site or field placement for pediatricians and other professionals in the field of medicine. Psychologists placed in such practicum placements have found this extremely beneficial in terms of being able to work with types of children who have not been traditionally covered in their preparation programs.

Summer camp programs are another area in which personnel gain experience in working with deaf-blind children. Many students who are finishing master's degree programs in working with the deaf-blind are hired as camp counselors, and students trained in other areas of education have been hired as aides. This enables students to have contact with deaf-blind children prior to working in the field and to learn their needs as they live together.

Staffing Models

Traditionally, one teacher was responsible for all aspects of programming for two children during the teaching day. The children were then turned over to house parents, who had a limited number of children to handle. This pattern resulted from the philosophy that students would have less adjustment to make if fewer people worked with them. They would be able to make more rapid adjustments and show greater achievement in this way.

Currently, the traditional model is seldom found. New models of staffing patterns have evolved because of lack of funds, large numbers of students, and too few formally prepared teachers. The most common staffing pattern today has one trained teacher supervising a number of aides, who interact with the children. This may result in the traditional one-staff-to-two-pupils ratio, but the number of trained teachers required and the costs are not as great. The supervising teacher is usually responsible for two or three aides and for programming. The supervising or master teacher sets objectives for the program, works with the aides to form both long- and short-term goals, and writes day-to-day lesson plans. The aides carry out the program planned by the master teacher. Both teacher and aides are involved in evaluating the progress of the children. A good team working this way can be extremely effective.

In some settings the teacher may have each child individually for a particular subject such as communication while the aides cover other subjects such as self-care skills. In other settings, the teacher and aides work only with assigned children. In still another variation, all personnel work with all children in all teaching areas.

Team teaching is another model that has been investigated for use with deaf-blind children. Although staffing varies from place to place, one might have a teacher who is trained in the areas of mental retardation teamed with teachers whose training is in the areas of vision and deafness. These three teachers would form a team and would deal with the children and their needs as they relate to specific disabilities. Another type of team might have a teacher who is trained in working with the deaf-blind working with teachers whose training is in the areas of elementary education and child development. In this team the teacher of the deaf-blind would take the initiative, helping the others prepare programs and lending support in areas in which they are not as knowledgeable

concerning implications of deafness and impaired vision. Teachers who have no expertise in deaf-blindness need the help of someone familiar with these dual handicaps on at least a consultant basis. Deafness and blindness in these children are not separate handicaps, but are intertwined. The resultant needs cannot be attributed to either deafness or blindness alone but to a combination of the two.

In the case of team teaching, one teacher should be designated as a lead, head, or supervising teacher. This has been necessary, regardless of the composition of the teams, because of the problems that evolve when no one is responsible for making decisions. However, some dangers are involved. Such a teacher may become dictatorial and may feel that her or his decisions are more important than the decisions of other team members. The greatest degree of effectiveness is achieved when all areas are covered and when a real team effort is achieved (Hart, 1972).

Team teaching offers many benefits: several areas of expertise can be included; staffing patterns can be varied so that individual work can be varied with group work; someone is present in case an emergency necessitates a teacher leaving the class; a child can be removed from the situation without the other children being left unattended; and considerable support from other team members can be utilized. Although team teaching means that several persons are interacting with each child, data show that the children adjust as long as there is consistency among the team members (Hart, 1972).

Another type of team model is composed of a teacher whose preparation is in working with the deaf-blind plus members from outside the teaching area. In this situation a physical therapist or occupational therapist may be part of a team, or a trained teacher may be teamed with a social worker and speech therapist. This team might be composed of various types of persons who deal with different aspects of human development. With course work, experience, inservice training and consultant help, teams with little initial expertise or background in working with the deaf-blind can become very effective in working with these children.

Sometimes a person with no background in working with the deaf-blind is recruited to deal with this population. The fields of child development, nursing, and speech have frequently been used to draw people into the area; and the surplus of elementary school teachers has provided people

with degrees for employment. Although some traditionally trained elementary teachers are not willing to feed and toilet severely involved deaf-blind children, others have been extremely creative in finding new ways to train these children and to meet their needs. Through careful selection of personnel with a willingness to interact with low functioning individuals, many of these people have been successfully retrained to work with deaf-blind children.

Skills and Attitudes Needed

Specific skills and attitudes necessary for personnel entering the field of service to the deaf-blind have previously been identified (*Preparation of Professional Personnel to Meet the Educational Needs of Deaf-Blind Children*, 1971). Some skills and attitudes overlap, while others are unique unto themselves. However, all personnel should have experience or acquaintance with each of the areas listed.

Two limiting or defining principles apply to all listings. First, information accumulated by a professional must be broad in scope yet directed toward his or her particular area of expertise such as teaching, administration, or guidance. Second, the person must have a great deal of role flexibility. The overall professional in the field must be able to shift from functioning as parent to caretaker to diagnostician to teacher to administrator to supervisor or researcher as required by his or her position. None of these roles is mutually exclusive in the service of the deaf-blind.

Experience with deaf-blind children is a requisite for all professionals, and contact with deaf-blind children throughout the training experience is essential. The types of required contact could include (1) program participation; (2) observation of the child alone, in a group, with the family, and in community settings; (3) clinical practice with one child or with a small group; (4) student teaching, and (5) internship. The internship should take into consideration the individual needs of the students as well as the individual needs of the client in the placement setting.

In addition, teachers should be familiar with the several types of teaching strategies that are widely applied today and should be skilled in choosing which strategies or combination of strategies would be most beneficial to a particular child.

Personnel Needs

A series of occurrences and developments dating from the middle 1960s have greatly expanded the

need for programs and professional staff to serve the deaf-blind population in the U.S. This includes the rubella epidemic of 1963-65, the legislation that has evolved since that time, and additional case-finding. The areas primarily affected by the increase in population and their changing needs are diagnosis, residential settings, vocational training, maintenance, and education.

At one time one or two diagnostic facilities were adequate to assess the needs of deaf-blind children. However, with the increased load, existing facilities and staff were found to be inadequate. Additional diagnostic facilities and the staff to operate them were needed. Medical personnel, audiologists, speech therapists, and educators—many of whom had never seen a deaf-blind child prior to the emergency needs of the early 1960s—responded; and now, with a substantial accumulation of experience behind them, they are ready to share their diagnostic expertise with others in their field.

As the majority of deaf-blind children—the rubella generation—grow older, new problems, requirements, and solutions are appearing in the area of residential living situations. Previously, possibilities beyond the natural home setting have been the foster home and, more often, institutions. Now, more and more options are being made available. Small-group homes, for example, are being developed in communities throughout the country. Deaf-blind children who are not able to remain in their own homes, but who in the opinion of parents and professionals can remain outside institutions, are being trained for placement in such homes. In some cases deaf-blind children are also being transferred from large institutions to these small-group homes. Training for professionals to staff these new settings should be given immediate priority. Institutional staff development is also important in providing the stimulation and training that these children need to make the transfer from the institution to another setting.

Along with the push toward group homes, prevocational programs have been initiated. It is felt that sheltered workshops may be a useful adjunct to group home life, keeping the residents' time occupied with meaningful activities as well as enabling them to make a monetary contribution to their support. This necessitates the development of a new type of personnel—professional people trained to function within a small-group home as well as within the workshop setting.

Prevocational skills is an area of skill development that only recently has been recognized and that has been subject to much discussion and

controversy. To some educators prevocational training means getting a child toilet-trained and mobile. To others it means a formal training program to develop specific salable skills. The issue will not be settled in this paper, but attention must be directed to the fact that personnel are needed to nurture self-help skills as well as to develop specific vocational skills. Personnel are needed to work in both of these areas.

Training concepts and expectancies with respect to vocational rehabilitation are also being adjusted to fit the needs of the deaf-blind population. Increasingly, counseling is being done in terms of the future life-style of the deaf-blind persons once they have gone through initial educational placement. Many vocational rehabilitation programs are providing inservice training sessions to sensitize their counselors to the needs and abilities of this population.

New needs can also be identified in education. For example, as the rubella population—those born in the mid-1960s, in particular—approaches puberty, there is increasing concern for providing suitable sex education programs. Many new areas such as music and art therapy have been used successfully with these children. Personnel must be made aware of these changing needs and must obtain additional training; or new personnel must be trained to fill these positions.

Specific types of personnel required to staff the educational, vocational, and residential settings for deaf-blind children and youth comprise a lengthy list. They include master teachers; classroom teachers; paraprofessionals; aides; child-care workers; trainers of paraprofessionals; regional coordinators; researchers; resource consultants; administrators; supervisors; directors; residential school superintendents; college teachers; physical and occupational therapists; guidance counselors; directors of social and recreational activities; liaison staff members between dormitory and classroom; and vocational rehabilitation personnel (*Preparation of Professional Personnel to Meet the Educational Needs of Deaf-Blind Children*, 1971). Erratic distribution and shortage of staff across the country have created variances in staffing patterns and in the use of these personnel.

Standards of Personnel

Little has been done on a national basis to establish uniform standards for personnel who are currently working with deaf-blind children. In most states certification officers have been accepting other types of specialization for certification.

Most states require certification in some area of special education, but others require only a minimal number of hours of special education course work. Attention must be given to improving the quality of services by upgrading the professional and nonprofessional staffs. The North American Committee on Services to Deaf-Blind Children and Youth (*A Committee on Standards Report*, 1971) has suggested general standards for different personnel that can give direction to programs.

Research Needs in Personnel Preparation and Use

The field of professional preparation in the area of work with the deaf-blind has many unresolved questions. Review of the known research shows a scarcity of information regarding such topics as methods of rendering personnel less sensitive to working with the severely handicapped person; the most efficient and productive means of preparing teachers, administrators, paraprofessionals, parents, and related personnel; population parameters for personnel and children; the most effective delivery systems; staffing patterns and staff-child ratio; creation of the least restrictive teaching environment; staff interaction and cooperation; studies of setting; identification of competencies; data collection, with a storage and retrieval system that would be easily accessible to the classroom teacher; sharing of nonpublished data; recruitment of personnel; the most appropriate trainers for personnel; cost-effectiveness; use of training packages; and needs assessment (Conference on Education of the Severely Handicapped, a conference sponsored by USOE [BEH], Division of Innovation and Development, Princeton, N. J., Educational Testing Service, 1975). More effective means of preparing personnel and of using them following their training cannot be determined until more is known with respect to these topics.

Summary

Much has been accomplished in obtaining and training personnel to work with the current population of deaf-blind children; but staff shortages still exist, and gaps are present in the professional expertise necessary for the most effective management of these children. Because formal programs for staff preparation are unable to provide adequate numbers of personnel, the majority of programs must rely heavily on inservice training for all types of personnel. Gains have been made in personnel preparation, but a great deal more is left to be accomplished, particularly in numbers to be

prepared, knowledge and skills to be gained, questions to be answered through research, and an expansion of the types of personnel to be trained.

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A Parent's View

Marjory Becker

Day-to-day existence with Jimmy, my deaf-blind, nine-year-old son, is similar to what life might be like if we built our house on a roller coaster with its peaks of excitement and valleys of anticipation, one crisis following another. The stage was set during his first weeks of life—a baby born ten weeks prematurely; suffering from the effects of Rh incompatibility and requiring exchange transfusions; and developing hyaline membrane disease and not infrequently being too weak to want to try to breathe. In short, few of his body systems were functioning. Somehow I knew that scrawny, jaundiced little creature was going to survive even when his nurses and doctors despaired. Every day I spent hours watching him through the windows of the nursery, willing him to live. Fifty-nine days later I finally got to touch him, to hold him, and to bring him home. Except for a hint of crossed eyes, he seemed quite normal, and it was not very long before we were rewarded with his first smile. I had no forewarning of the life that would follow for us.

By the time Jimmy was six months old his eyes were decidedly crossed. I took him to an ophthalmologist, and the doctor announced bluntly that my baby was blind; optic atrophy with slight vision in his right eye, none in the left. Glasses would be of no benefit to him. My next visit was to the pediatrician. He confirmed my suspicions that Jimmy had cerebral palsy. Soon after this distressing news from his doctors, Jimmy delighted me by holding his own bottle. But my pleasure was short-lived. I was told he was deaf. That blow was softened somewhat when Jimmy was fitted with hearing aids and that very same day sat up by himself for the first time. Small gains for Jimmy and major shocks for us became a way of life during those first few years.

At the age of thirty-two months, Jimmy's only means of moving from place to place was to squirm on his tummy and inch across the floor. Although occasionally he would attempt to move toward any kind of light, especially sunlight, he spent most of his waking hours lying on his back. In the spring of 1968, I heard that a swimming pool especially designed for the handicapped was being opened in Long Beach, California, and would provide free lessons. I had a feeling that exercising his body while being supported by the calming effect of the warm water might help Jimmy strengthen his muscles, and I hoped that he would eventually be able to duplicate these motions out of the water as well. At least twice a week, often four times, I would take him to the swimming pool, get into the water with him and, with a hand under his head, guide him over the surface of the water. In a matter of weeks Jimmy was able to float by himself. Soon he was rolling over and over using his own strength and even finding his way to the pool's edge. He not only became noticeably stronger from the exercise, but he also began to move his legs out of the water as instinctively as he did in it. Water proved to be a great aid to his development as well as his main source of pleasure. All of these results nurtured my hope that Jimmy could benefit from specialized training. I began my long search for a program for him.

Jimmy had reached the age of four unable to walk and unable to express his needs except by screaming. He did not belong with the deaf or with the blind. School classes for orthopedically handicapped children were closed to him as were those for the mentally retarded. I contacted local, state, and federal agencies. I spoke with educators, social workers, doctors, almost anyone who had even the remotest connection with programs for the handi-

capped. As so often happens, just when one is ready to give up, an answer appears. In my case a compassionate social worker located a special class about to be started for deaf-blind children in a public school specializing in educating blind children in Hollywood, California. With a minimum of red tape, it was agreed that Jimmy should have a trial period in the new class. The class that Jimmy was to attend was experimental: any child who made gains as the result of the program would be permitted to continue in it.

School started just a few days before Jimmy's fifth birthday. Quite naturally I was apprehensive about Jimmy's trial period, but my concern proved unwarranted as Jimmy "passed." I marveled at the patience and dedication of the teachers and aides who created new ideas and solutions to some of Jimmy's problems. A major benefit was his exposure to persons outside of his immediate family. This type of experience helped him to learn to adapt to new situations. Jimmy made steady progress because of the concentrated attention he received; and he remained in the program for two years.

During the time Jimmy was attending school, an orthopedic surgeon suggested that by surgically lengthening the heel cord tendon of Jimmy's left leg, he might possibly be able to stand without support. The operation was performed, and it, more than any other single event in Jimmy's life, made possible a giant step forward. Two months after the cast was removed he stood up—two feet on the floor—with a stability that he had never had before. An even more dramatic change was his becoming vertically oriented. This led to a whole new world of sensation opening up for him. At age seven and a half, Jimmy was walking independently. But he was no longer attending school.

In June, 1972, we had left California to relocate in Nevada. Before we moved to Las Vegas, I had inquired about schooling for our ten-year-old, cerebral palsied daughter, Mitzi, whom we had adopted the previous year. She is a sweet child with severe motor damage and is unable to walk unaided. She, too, needed special education. We learned that Las Vegas had an outstanding program, well-suited to her needs. However, no program for the deaf-blind existed anywhere within the state. At that time Nevada was sending its deaf-blind children to Arizona for schooling. I refused to enroll Jimmy in the Arizona program. I believed that there had to be some alternative and a better solution to the problem of educating special

children. With few misgivings I kept Jimmy home with us that year.

Another factor that affected my decision to keep Jimmy home was our anticipation of a trip to Berkeley, California, to the Evaluation Center for Deaf-Blind Children. He was scheduled to go there early in the school year, but with cancellations and the usual delays we did not make the trip until April, 1973. In the process, Jimmy had been deprived of one crucial year of special training—by my decision not to enroll him in the residential program in Arizona and by the lack of a school class for him within the Las Vegas school system. The evaluation was well worth the wait. I felt, and rightly so, that the findings and the report of the experts at Berkeley would be important in determining the proper type of program for Jimmy.

In the fall of 1973, Nevada started its first program for deaf-blind children at the Mental Health Institute in Sparks, a few miles outside of Reno and 440 miles from Las Vegas. This development left me with the same dilemma that I had faced the previous year: Jimmy could remain at home and receive no schooling or he could attend a program located at such a great distance from home that it would mean rare opportunities for visiting him and his being at home only for major holidays. Once again a school year began, and once again Jimmy did not participate in a school program.

My frustration was growing, and I began to seriously consider mounting a campaign urging the authorities to establish a special class for the deaf-blind children who were residents of Las Vegas. My timetable was interrupted by Adam, a bright, seven-year-old blind child with whom I had become well acquainted at the California School for the Blind while Jimmy was being evaluated. Adam became a part of our family at Thanksgiving time, and my husband and I were appointed his legal guardians. We were overjoyed that he would be allowed to attend regular school classes with healthy sighted children in the Las Vegas school system. As soon as Adam became adjusted to our home and was admitted to school, I again turned my attention to my efforts on behalf of local deaf-blind children.

In February, 1974, I was able to persuade the administration of one Las Vegas school to give Jimmy a trial period in its class for the multi-handicapped. The trial proved to be a disaster. I should mention that by this time we were aware that, in addition to his other handicaps, Jimmy was hyperactive, potentially epileptic, and asthmatic.

Despite the variety of his disabilities, he was seldom ill and had missed very few days of school in California. However, the nature and extent of his handicaps were a factor in his being allowed to remain in this class for only three days. At that time it became apparent to all that a class of ten children with one teacher and one aide was not suitable for Jimmy and that in such a class setting his special needs could not be met. Another door had been closed to Jimmy, but it was not an entirely futile three days. It made the local authorities more aware of the fact that deaf-blind children must have programs specifically designed to meet their unique needs. Once again, we were faced with a major decision.

The Chinese use two characters to designate the word "crisis"—danger plus opportunity. This definition seemed especially appropriate when applied to the crisis that was developing over Jimmy's schooling. The *danger* lay in keeping him at home still longer and further denying him his right to the training that only experts could provide and that he so urgently needed. The *opportunity* was to increase and to intensify my demand to have a program for deaf-blind children started in Las Vegas. Other deaf-blind children would benefit from a locally based program; and I hoped that if my efforts were successful, a precedent would be set for still other handicapped children whose schooling needs were not being met within the community. There were some who criticized my decision not to enroll Jimmy in the residential program at Sparks while I worked toward the establishment of a program near his home, but I felt that the program at Sparks was for the children a gathering place in which they were isolated from a normal environment. These feelings were augmented by a growing body of scientific evidence that home is where the child's base should be. I was firmly convinced that my case would be weakened if I capitulated under pressure rather than holding to my intense beliefs.

Currently, a number of studies are in progress throughout the United States comparing a home atmosphere to that of institutional care. Reports from some of these studies strengthened my conviction that a child who is an integral part of a warm, loving family will gain more fulfillment, more confidence, more independence, and more social awareness than is possible within the finest institutional setting. I believe that a child develops in a manner appropriate to the environment to which he is most consistently exposed. If he is constantly, day in and day out, living with deaf-

blind children, he or she will be unable to function in anything other than a deaf-blind society. If we believe that the normal child develops his or her skills and survival attitudes through interactions with many segments of our society, then how much more crucial it is for the handicapped child to have the same opportunities. If these special children are isolated by institutionalization, then, I believe, we are advocating nothing less than social euthanasia.

A letter to parents from the John Tracy Clinic states:

No matter what educational plans are worked out for your child, or whether he—or she—is in school at this time, *you* have a job. Any gains your child makes, any skills and abilities he achieves, will be due in large part to what you do in your own home to help him learn and develop.

How can parents learn the techniques used in a school program located 400 miles away from home? How can they practice these techniques with the child when he or she is at home only for short periods? I believe that many, if not most, deaf-blind persons will require some continued family supervision as adults. The family that is not intimately involved in the training of their child may choose not to be involved at all in later years. The child will be an enigma to them; the adult, a stranger.

Despite these strong beliefs, I felt that in fairness to all concerned I should visit Nevada's program for deaf-blind children. Soon after Jimmy's trial period in the Las Vegas class for the multihandicapped, the two of us made the 440-mile trip to Sparks.

I was very favorably impressed with the staff of the deaf-blind program. The personnel were not only highly competent, but also thoroughly dedicated to their charges. I loved the children and could see that they were making progress in areas that Jimmy was not because of the concentrated training they were receiving. I was less pleased with the facilities, which consisted of two sleeping rooms and one small classroom. The recreation room and bathrooms were shared with the young severely mentally retarded patients. Nevada plans to replace the building in two years, as it does not meet fire and other safety standards. With mixed emotions I left Sparks in the middle of the afternoon and arrived home in the early morning hours.

Several months later my husband, who is Jimmy's stepfather, had the opportunity to visit the deaf-blind program in Sparks. He shared my

feelings that Jimmy should be kept at home, and I was glad that my reservations were not just those of an overly protective mother. We agreed that it was our duty to do all in our power to obtain suitable schooling for Jimmy near our home.

I did not expect it to be an easy task to persuade school officials to initiate a program for the deaf-blind children whose families were Las Vegas residents. We started by laying out a plan of action. I wanted to be prepared to answer as many of the arguments as possible that might be presented as reasons for not starting this very special program. I wrote to the Department of Health, Education, and Welfare in Washington, D.C., and requested copies of court cases that pertained to the education of the handicapped. A number of recent court decisions are helpful in that they emphasize the rights of all children to have equal educational opportunities, and, in some instances, stress the need for community-based programs. I obtained copies of Nevada's education codes. I contacted the Southwestern Region Deaf-Blind Center to become familiar with the support services it could offer the school system. I inquired about available space in the existing schools. I researched the number of deaf-blind children who had been identified in Nevada and in which communities they resided. I spoke with several parents to determine their interest in having a program in Las Vegas. At the time of my visit to the deaf-blind program in Sparks, six children were enrolled in it, of whom four claimed Las Vegas as their residence. Several other deaf-blind children have since been identified in the state, but because of the remoteness of some of the rural areas, an accurate count is difficult. I asked about possibilities for respite care so that families would be assured of temporary relief from their responsibilities. Financial considerations often make the best possible arguments, so I obtained figures on the relative cost to the state and its taxpayers of institutional care, foster home care, family home care, education, and other support services. I attended school board meetings to familiarize myself with the attitudes of individual members toward special education programs and needs. I wanted to be as well prepared as I could be with the many areas that would be important in planning a new program.

Once the information was collected, I wrote a letter, or perhaps it might be called a report, as it was quite lengthy—seven pages in all. I sent copies to each of Nevada's members of the United States Congress; to the Governor, Mike O'Callaghan; to the Clark County School Board and its Department

of Special Education; to the State Superintendent of Public Instruction and his consultants to special education; to the State Director of Services to the "Blind; to Robert Dantona, Coordinator, Centers and Services for Deaf-Blind Children at the Bureau of Education for the Handicapped, U.S. Office of Education; to William Blea, Director, Southwestern Region Deaf-Blind Center; and to a local newspaper, the *Las Vegas Sun*. The responses I received were encouraging. Two results especially delighted and surprised me. The *Las Vegas Sun* based a lengthy editorial on my letter entitled "Special Children's Program Requires Top Priority." The article stated, "This mother is making a legitimate demand upon the state in behalf of her own child and those others in similar circumstances, and certainly her plea cannot go unheeded." I considered such support from a newspaper to be a major bonus in my campaign. Several weeks later, I received a letter that made me even happier. Governor O'Callaghan wrote that he had requested the Director of the Nevada Department of Human Resources to appoint a study team, with one of its major goals being the establishment of a program to meet the needs of my son by the following September. The letter was dated May 20, 1974. I was thrilled; and it did not occur to me to be anything less than optimistic about there being a local school program for Jimmy in the fall. In my naivete I was not unduly concerned that the letter that had gone unanswered was the one to the local school board.

The Governor's task force first met to determine a course of action and subsequently came to Las Vegas in June. A conference was held with school officials and administrators and others whose services would be required for a program for the deaf-blind. Dr. Blea represented the Southwestern Region Deaf-Blind Center and made the trip to Las Vegas to assure the school authorities of the center's support for such a program. I was not invited to attend that meeting, but apparently many questions were raised about the availability of other types of support services that were considered to be necessities beyond an actual school program. I received information that some parents of deaf-blind children had been approached with questions such as "Do you really want your child returned to your home in Las Vegas with only a few hours a day of relief from his care which a school class could offer?" A second meeting was held for parents only. Their actual needs and wishes were discussed. I felt the general attitude was one of guarded enthusiasm for a local

program. My husband made what I thought was an excellent point when he asked what parents would do should they move to another state where no residential facility was available and where they would suddenly be faced with the prospect of including an almost total stranger—their very own child—in their home. Another parent said that if her child were to live at home, there would be an increased need for good coordination between teachers and parents. I did not want to antagonize other parents by expressing my views on the essential shortcomings of any institutional-type care. In fact, I have never felt that I have the right to be critical of any family that finds itself, for any reason whatsoever, unable to care for a child. I would hope, however, that families faced with what must be a most difficult decision can be helped to make their choice with freedom from guilt. Hopefully, one of the choices open to them is that of placing their child in a suitable foster home. In his fascinating book, *Birth Rights*, Richard Farson has a chapter devoted to the rights of children to alternative home environments. He points out that merely giving birth to a child does not necessarily prepare one for the responsibilities of being a parent to that child and that should parents be unable or unwilling to provide a suitable environment, the child's rights are of first importance. He suggests a number of different arrangements that could be considered to provide proper care for the child.

The final report of the task force was not presented to the Governor as early as had been anticipated. During the summer months, I was able, to some extent, to maintain contact with the committee and with sources close to the committee. I was aware of the diminishing possibility that a Las Vegas program specifically for deaf-blind children would be a reality by the fall of 1974. My husband and I had serious discussions concerning what steps we might take to accelerate action. He has had considerable political experience in California and Washington, D.C., and feels that individuals with causes are often defeated by political time-tables. He believes that they run out of time and resources at the very moment that they should be forcing an action. He wanted to apply pressure on all the decision makers who were involved in providing schooling for Jimmy. His arguments were very strong, and ordinarily I would have deferred to him; but in this case, my philosophy prevailed: patience, perseverance, and politeness—plus a continuous stream of letters. Not that I adhere to all of those things all of the time. For instance, I

became really annoyed by one particular letter that I received from a state official, and I accused him, in writing, of using “semantic . . .” (expletive deleted). It was a mistake in judgment on my part and did not help my cause.

In August, 1974, a nice thing did happen—a coordinator for programs for the deaf-blind in Nevada was appointed by the Southwestern Region Deaf-Blind Center. I found that I not only had a new friend, but also that, even more importantly, here was someone trying to obtain services for all deaf-blind children in Nevada. A school program for Jimmy was high on her list of priorities. She has been in charge of the efforts to establish a program since Governor O'Callaghan reviewed the task force report in September, and she wrote to me that one of its several omissions was “a complete description of a feasible program for the Las Vegas area.” My initial reaction to the news was one of despair. However, there were glimmers of hope as the Governor indicated that there would be a continuing investigation of the means of providing an educational setting for deaf-blind children in the southern part of the state. He further suggested that Jimmy should be accommodated, prior to the formation of such a program, by some special education class in our community.

A nine year old who does not attend school—that is appalling! By the fall of 1974, I was tired of being penalized for doing what even the experts say is the proper thing—keeping my child in his home atmosphere. After receiving Governor O'Callaghan's letter, I waited a few weeks, hoping that the Clark County School Board or its administrators would respond to the Governor's prod and that a class would be found for Jimmy. Their policy of silence toward me continued, and I wondered if they thought that by ignoring me and Jimmy and our legitimate needs we would somehow disappear. When the school board did not initiate action within a reasonable length of time, I asked for a conference at the Las Vegas facility for mentally retarded youngsters. The principal readily agreed to a meeting. Attending the meeting from the school were the principal, a teacher, and a social worker; and they had done their homework. Each one had taken the time to study all of Jimmy's available records. Besides myself, the coordinator for programs for the deaf-blind in Nevada and the local director of services for the blind took part in the conference. The school was willing to try Jimmy in one of its programs, and we who represented Jimmy agreed that the class under discussion was the most ideally suited to

meet his needs. The Southwestern Region Deaf-Blind Center was prepared to pay the salary for a teacher's aide to help work with Jimmy. Again I was excited at the prospect of Jimmy's starting school. I soon learned that what should be a simple enrollment procedure can become complex and can drag on interminably, or at least so it seemed to me.

Fortunately for Jimmy, he was getting a few hours a week of special attention. Early in the fall I had placed a notice on the bulletin board of the special education department at the University of Nevada at Las Vegas. I described Jimmy and explained that we were looking for someone, regardless of experience, who would be willing to work with him for five or six hours a week. The idea was not mine but came from the western region representative for the National Center for Deaf-Blind Youths and Adults. We felt as though we hit the jackpot when a student saw the notice and responded. Jimmy's tutor was a freshman at the University, in her second year of tutoring at the local school for deaf children. She is exceptionally bright, creative, and mature. I was able to supply her with a considerable amount of reference material to give her some starting points in working with Jimmy. I had the list of suggested activities that was part of the report prepared by the Evaluation Center for Deaf-Blind Children in Berkeley, and I had our lessons from the John Tracy Clinic course for parents of deaf-blind children. In addition, I gave her various articles by authorities on the training of deaf-blind, such as those from Dr. J. van Dijk from St. Michielsgestad, Holland. I also included all of my workshop papers from various conferences sponsored by the regional centers for the deaf-blind. Next, I enlisted the aid of my daughter-in-law, who just turned twenty-one and is the mother of two youngsters. As a part of our basic family group, she has helped for many years with Jimmy in a less official capacity, and she is obviously one of his favorite people. The outstanding trait of these two young girls is their endless patience—a trait that I may share as a mother, but not as a teacher. Just the few hours a week these two girls have given to Jimmy have produced noticeable results. For example, he now uses his residual vision by choice and more effectively, and he finally is able to oppose his thumb and forefinger to pick up small objects. Jimmy's gains from this limited attention served to point up his need for a continuous program.

In January of 1975, I was told, and then received written confirmation, that Jimmy would

start in a school program on February 10. The day came and went and Jimmy remained home. The next date set was for March 3, and that, too, passed without results. I firmly believed that Jimmy would start school in April, and I refused to be disheartened by what I felt, by then, were only temporary setbacks. At least all signs finally seemed to be in our favor.

And start he did. On April 7, 1975, Jimmy spent his first official day in school in almost three years! A stroke of magnificent good luck helped make my wish a reality. A teacher with experience with deaf children had recently moved to Las Vegas with her husband and had contacted the school administration about possible openings. She accepted the position of full-time aide for Jimmy, and the last obstacle to his attending school was overcome.

The first week, the aide came to our home each morning, helped prepare Jimmy for school, and rode the bus with him to attend the afternoon session. Jimmy's adjustment was so quick, and his need for a crash training course so apparent, that school personnel decided that he could attend class on a whole-day basis, starting his second week. He has now been in school for just four weeks. Every one of us is delighted with his progress. Jimmy's first "A" was for learning to walk from the bus to his classroom carrying his own lunch pail. He is doing a considerably better job of feeding himself. He is more interested in exploring his environment, visually and tactually. He is more responsive to commands that are given verbally and by signing. The school physical therapist discovered that Jimmy's left leg is not only atrophied but is also almost an inch shorter than his right leg. With a built-up sole on his new shoes, his walk is much more steady and he is able to navigate a balance beam with minimum support. The overall attitude of the teaching staff seems to be to view Jimmy as a challenge and as a child with potential. And I am so very happy, I wish there were a bigger word.

In recent months, the delays in getting Jimmy started in a school program were increasingly hard for me to understand, but when I felt impatient, I could look back at the record and receive a large measure of satisfaction from the gains we had achieved. Perhaps even more important than Jimmy's attending school immediately is the fact that a specific class for deaf-blind children has been included by the Clark County School Board in the planning for new programs starting in September, 1975. Not only will Jimmy attend the new class, but also Las Vegas parents whose children are now in the Sparks program will have the choice of

bringing their children home or having them continue at the Mental Health Institute as their situations and needs dictate. The children who remain in Sparks will leave the institute each day, as their special class will be held within a public school building, thereby affording them a measure of integration into the community.

With his continued intensive training, I feel confident that Jimmy will make gains in new areas. Except for pulling his pants up, he does little to dress himself, which is one goal. Toilet training will continue until he is in complete control. My greatest hope is for improved communication. Now, for example, Jimmy "tells" us his needs by taking a hand and leading its owner to the refrigerator to indicate he would like a drink. Our communications to him are, if anything, even more limited. The day may arrive when we will be able to remove the locks from Jimmy's bedroom door and the bolts that fasten our lamps to the tables. The only time Jimmy needs a minimal amount of supervision is when he is swimming. During the warm months, he goes out to the pool by himself and climbs in and out of the water at will, spending hours each day indulging himself in his greatest love. We will never know the full extent of the benefits of his swimming, but we are convinced that it has been of enormous value.

Our efforts to obtain a school program for Jimmy have been fruitful, but success would not have been possible without the contributions of many concerned people.

I have learned one fact over the years—the more I care and share my feelings with others, the more they care. My enormous desire that my children develop their potentials and lead good lives in as normal a way as their handicaps make possible seems to create the same interest in the many people with whom they come in contact. The end result is help for the children in many ways from many sources. I am especially grateful to Governor O'Callaghan; the *Las Vegas Sun*; William Blea, Director, Southwestern Region Deaf-Blind Center; Linda Begbie, Coordinator of Deaf-Blind Services for Nevada; Ken Hehr, Director of Services for the Blind in Southern Nevada; Jim Verby, Regional Representative of the Department of Health, Education, and Welfare, and one member of the administration of the Clark County school system, Dorothy Seigle. Others have been helpful, but I

cannot mention all their names, as some acted beyond their "job descriptions" because of their personal conviction that the cause was right.

The many members of our family deserve special tribute, for each one contributes something to our unique brood. I do not mean to imply that they are all do-gooders. Not all of them work with or understand Jimmy, nor, on the other hand, do they ignore him—he is very difficult to ignore. But we have never had any of our children strike or tease Jimmy. They seem to know instinctively that he is the defenseless one, and they treat him with kindness. Our special children also have plenty of healthy, normal children from our neighborhood as their regular playmates. We do nothing to encourage or discourage the ebb and flow of children into our home. They play with our children by choice—and isn't that the way it should be?

Special kids enrich our lives in many ways. The many and varied experiences that have been my life for the past nine years are my treasures. I would not trade with anyone, anywhere. Jimmy has taught me the power of love, love that can pass through the glass walls of an incubator, that can touch a deaf-blind child closeted from reality by the nature of his handicaps. Gustav Eckstein wrote in his book, *The Body Has a Head*, that "rarely, but it does happen, a person is born both deaf and blind, from the beginning heard no evil, saw no evil, thought no evil." I am not saddened by a nine-year-old child who has never known jealousy, never purposely hurt anyone in any way, who has never known hatred. He teaches me, and I have found that there is much to learn from these children.

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Research Needs in the Area of the Deaf-Blind

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Predictions that are accurate to within a few miles can be made regarding how closely huge rockets will hurtle past distant planets. Valuable mineral resources hidden beneath forests, deserts, and mountains can be mapped with precision by using satellites to scan large areas of the earth's surface. In July of 1974 cosmonauts and astronauts from the Soviet Union and the United States completed a monumental linkage of space-ships high above the earth that augurs to be both real and symbolic.

Science has made it possible to isolate and destroy, among billions of neurons in the human brain, those few cells which give rise to epileptic seizures without the wholesale destruction of nearby healthy cells, but when it comes to understanding the complex dimensions of deaf-blind children and helping them achieve their unknown potential, we are far less powerful. Those two giants—research and technology—have not yet produced a solution to the uniquely varied needs of this multihandicapped population.

Reams of paper would be needed to catalog the issues that relate, directly or indirectly, to the life of the deaf-blind child. Technological advances in the development of hardware providing intelligence analogues, implantation of electrodes into the occipital cortex for "artificial vision," and the development of highly sensitive scanning devices to permit the deaf-blind "to read" tactually are part of our present reality relating to deaf-blind children.

The economics of rehabilitation show that the more severely impaired an individual is, the more costly are the educational and technological services which must be provided to offset the handicapping conditions. That which training may not be able to accomplish, technology might. For example, the

National Center for Deaf-Blind Youths and Adults has cooperated with the New York University Deafness Research and Training Center to develop and field-test a remotely activated tactile signaling device for deaf-blind persons (Schiff and others, 1973). This device permits contact to be maintained with deaf-blind persons even when they are out of sight of a supervising individual. Testing of the signaling device is being accomplished in both living and vocational settings, and the findings of the study have generated specific engineering modifications that will improve the flexibility and serviceability of the system. The educational applicability of the device is profound. Students can be allowed greater independence of operation without jeopardizing their safety, and teachers can more easily meet the supervisory needs of a group of students within an instructional setting.

However, technology is still in the development phase without direct applicability to the daily life of all deaf-blind children. Although the amount of medical research into etiology, epidemiology, and incidence of deaf-blindness appears to outweigh educationally focused research, the authors will not presume to introduce specifically medical findings into this paper. The focus of this document is educational research, and the authors will summarize findings which are immediately accessible to the educational specialist. Because extensive bibliographies chronicling publications in the general areas of human exceptionalities can be readily obtained, this paper will be restricted to those research studies in deaf-blind education utilizing deaf-blind populations exclusively. The studies reported are directly related to the inevitable intent of all interventions into the life of a deaf-blind child—the successful habilitation of the child into the larger community.

Background of the Problem

Specialists in the education of deaf-blind children have perhaps the most eclectic backgrounds of any professionals in special education. Not only have deaf-blind educators tended to be drawn from a multitude of other specializations (e.g., education of the deaf, education of the blind, and educational psychology) but they also have been obliged to utilize data derived and developed with populations other than deaf-blind children. The ease with which empirical findings from studies of deaf, blind, or multihandicapped populations are generalized to the deaf-blind is simultaneously the field's greatest asset and its greatest shortcoming. That generalization is an asset in that the field of deaf-blind education has been able to come a long way in a short time by profiting from the successes—and the mistakes—of other specialties; it is a shortcoming in that the transfer of data has not encouraged new, innovative approaches to research in the area of deaf-blind education. More importantly, the ready access to successful approaches in parallel fields of human services has lulled deaf-blind educators into what might be a false sense of security. The findings of empirical studies with the deafness, blindness, or other exceptionalities are complacently accepted as valid when applied to the deaf-blind population. As a result, there is little or no empirical validation that the techniques used successfully with other exceptionalities are also appropriate techniques for use with a deaf-blind child.

With the habilitation of the child as the paramount objective, to question why funds sorely needed for direct service intervention have been diverted into academic research projects is certainly reasonable.

Successful education intervention with deaf-blind children is the outcome of sound principles and strategies. Such strategies are most efficiently and economically developed through careful, systematic research. Without the objective verification afforded by controlled research data, specialists in education and other habilitation services have only personal speculations or biases to guide their decisions in the planning, implementation, and evaluation of services to deaf-blind children.

If research is so important, how well are we doing in providing the educational interventionist the objective information he or she needs? The answer is not encouraging.

Research: The Pessimistic View

A review of research literature applicable to the education of deaf-blind children presents six major

limitations in the quality and quantity of available information. First, the number of empirical studies utilizing deaf-blind children as the focal population appears to be extremely small. Second, very few true research reports exist to offer objective guidance to educators. The literature available consists primarily of case studies, narrative program reports, or position papers by workers in the field. Third, of the limited number of research reports which are available, many appear to be too esoteric or molecular in their focus to assist the service specialist in the day-to-day delivery of services. Fourth, potentially helpful reports of research conducted appear to have a restricted distribution. Their existence is often known only to a few individuals or agencies. This denies specialists who are dispersed throughout the nation in satellite service centers access to valuable information. Fifth, many articles or pamphlets offer "how-to" or "how-we-did-it" information, but few data are presented on other than an anecdotal, experiential basis to substantiate the economy or efficiency of the techniques endorsed. Sixth, while diverse agencies and individuals across the nation may actually be conducting research, few are reporting the results of that research. It may be that the impetus for research has already arrived, but that we are in the midst of a "data lag." Perhaps it is too early to report anything but a few tentative notes on the progress of the research efforts themselves. For example, the National Center for Deaf-Blind Youth and Adults includes in each annual report a section devoted to the research activities of the center. In each report progress is described on the development of hardware designed to assist the deaf-blind person to cope with living in the sighted and hearing world. Focusing primarily upon communication aids (e.g., Telebrailier, Wrist-Com, the General Electric Communication Aid), the center's reports offer encouraging optimism that research efforts may be simply unpublicized, rather than nonexistent.

The authors, therefore, suspect that many dollars of scarce service funds may be supporting programs that are employing techniques and strategies of unproven merit and that are operating on the basis of imprecise—or even erroneous—developmental principles.

Historically, as federal, state, or local fiscal resources are tightened, research activities are among the first to be curtailed. Thus, at the very time when getting the greatest amount of benefit out of the available dollar is most critical, the method most likely to identify and develop eco-

nomic, efficient service strategies is eliminated. Although a greater resistance to curtailment of research is apparent today, we are now faced with a dearth of quality information because of past vulnerability and lesser priority. If we expect the specialists of the 1980s to be better informed, the research momentum must be increased now.

Research to Date

One safe assumption is that efforts to prevent potentially handicapping conditions are as valuable as intervention efforts once the condition has occurred. Much effort has been directed to preventing conditions with associated sensory impairments. The reports relating to the development of the rubella vaccine and the resulting incidence studies (Meyer, 1968; Goldstein, 1968) have documented the need and the effectiveness of specific immunological approaches in the prevention of deaf-blindness. The rubella surveillance publications by the Center for Disease Control (CDC) offer timely, accurate data describing incidence, status of national immunology efforts, and special investigations underway that focus on rubella populations. In this same vein, the congenital malformations surveillance publications, also published by the CDC, broaden the analysis beyond the restricted scope of rubella to all congenital anomalies reported in infants born in three localities (metropolitan Atlanta, Nebraska, and northeast Florida). As stated in the documents themselves "... data are collected by special surveillance programs which use hospital reporting systems to identify newborn infants with malformations."

Data contained in this report are preliminary and are provided solely for the information of persons interested in epidemiology of congenital malformations. Cooper (1968) anticipates the widespread use of successful immunological techniques in the protection of communities against recurrent rubella epidemics. Cherry (1974), however, has doubted the success of the present national rubella vaccine program, citing incidents in which "herd immunity" concepts of immunization did not protect the overall population of the community. He also describes his concern that "haphazard" immunization programs could lead to a greater problem than that existing prior to the availability of the rubella vaccine. Both Cooper and Cherry emphasize the need for continuing research and development in the effort to produce a more effective vaccine than those currently available.

Educational Intervention

Using principles which have been proven effective in other populations of exceptionalities, education specialists have emphasized three major concepts in the delivery of services for habilitation of deaf-blind children. Simply stated, these concepts are: (1) intervene as early in the child's life as possible; (2) emphasize the development of compensating sensory skills; and (3) focus on the development of language and communication skills as a priority. With these concepts predominating, it is not surprising to find that the majority of research has coalesced around these three topics.

On the basis of the standard established by developmentalists such as Gessell, Ilg, Kagan, and Piaget with respect to the ontogeny of behavior, much emphasis has been placed upon early infant enrichment. Despite the well-established core of data that support early infant enrichment for intact infants, mentally retarded infants, and infants with single sensory impairments, the authors discovered no empirical evidence that substantiates the applicability of the concept to deaf-blind children. That common sense suggests its relevance is indisputable. What is disturbing is that no objective evidence exists to identify to the infant stimulator the primary needs, prerequisite skills, or most immediate objectives of enrichment programming. However, position papers and personal opinions abound. This is not to denigrate the excellent position papers available to interested readers. Many of them provide valuable guidance to the clinician whose client is deaf and blind. However, with the recent findings published by Kagan (1974), which call into question the "critical periods" concept for acquisition of specific developmental skills, the lack of empirical data identifying the precise value of early intervention with the deaf-blind youngster presents a troubling question. If we are willing to generalize findings in other specialties (developmental, psychology, physical therapy, and so forth) into work with deaf-blind children, must we not also generalize those findings which may call long-respected dogmas into question? Without data to the contrary, it seems to the authors that such must be the case.

Sensory Development

Many programs of direct services to deaf-blind children can be observed that employ similar techniques (e.g., sensory stimulation). Yet few researchers or reporters have attempted to define,

in concrete behavioral terms, just what sensory stimulation is and what it is purported to do. Because of this ambiguity, some programs are tacitly encouraged to implement what they assume sensory stimulation to be, rather than what it actually is. Little empirical discrimination has been provided between sensory stimulation and sensoriperceptual integration. Yet, the clinician should definitely know when the use of one technique or the other would be more effective. Most programs tend to employ either a "shotgun" total sensory approach, while others focus more exclusively upon visual or auditory training. The writings of Jean Ayres (1973) are perhaps the most definitive in her perspective of integrative functions for all sensory modalities. While stating clearly that much of her work is based upon a hypothetical model of arousal function (1973), she has been able to provide concrete data relating to the efficiency of her techniques. The authors conclude, after an extensive review of available literature, that Ayres' data contain the only discrete findings focusing specifically upon the deaf-blind child.

Another area receiving attention in sensory training is that of the proprioceptors. Bobath's techniques of neuro-developmental treatment have found popular appeal in working with the young cerebral palsied child (1962, 1967) due to the clarity of the theoretical foundations of the approach and the tangible success typically evidenced by children receiving this particular form of physiotherapy. As service programs for deaf-blind children expand their focus to include the severely motorically handicapped child with deaf-blindness, Bobath-oriented physical therapists are frequently called upon as educational adjuncts. Since the physiological structures of the deaf-blind child and sensorily intact child are basically equivalent, the relevance of Bobath's techniques to improving the function of the motorically handicapped deaf-blind child would seem to very direct. Many of the principles are based upon the foundation that adequate postural reflexes are prerequisite to the establishment of more complex developmental skills. An analysis of the benefits to be expected from Bobath approaches used with deaf-blind children should be available before educational specialists attempt to establish a superstructure of developmental objectives based upon the physiotherapists' foundation.

Language Development

The production of educational materials has been ongoing since 1970. The peak is not in sight,

and few refinements have been made in elaborating the topics presented at the inservice training workshops. The result appears to be a collection of subjectively derived generalizations concerning a wide variety of perceived educational or social needs of the deaf-blind child. Despite lengthy bibliographies suffixed to the articles reviewed, empirically derived sources of information to document the positions expressed appear to be lacking.

Current Status

After an extensive review of articles, periodicals, workshop proceedings, and comprehensive annotated bibliographies, the authors have regretfully concluded that empirical research focusing specifically upon the development and education of the deaf-blind child, *per se*, is practically nil. Because of this shortcoming in the field of deaf-blind education, the authors strongly endorse subsidized research programs designed to define more clearly the problems of the deaf-blind child and to delineate more succinctly effective methods of educational interventions.

Research should not, however, be permitted sacred-cow status. Judicious use of funds and a disciplined determination to fund with greatest priority those research studies which can be defined as system-essential can provide the necessary balance between research and direct-service activities. To this end, we propose the following as a brief sampling of the range of general research topics with direct service applicability.

Incidence Studies

Investigational studies into incidence serve two important purposes: First, realistic priorities cannot be implemented without an accurate determination of the incidence and prevalence of deaf-blindness in persons under twenty-one years of age. Second, the manpower and financial logistics of screening and identification necessary to determine incidence may serve to make state administrators and governmental bodies more aware of the scope of the deaf-blind issue and the meager support currently available. Visual and auditory screening of all residents in large state institutions for the deaf, the blind, the mentally retarded, and the mentally ill may reveal a dramatically larger service population than is currently described in population estimates. This would help elevate the perceived severity of the problem from the second-class (i.e., low-incidence) status that

seems to have been ascribed by state special education administrators and state legislators.

Language Development

The difference of opinions regarding the use of manual communication has not been an especially vocal controversy. The manual methodology is accepted by the majority of teachers in programs for the deaf-blind. Teachers appear to be comfortable in teaching what is known as "total communication" skills. Unfortunately, adequate research into comprehension of manual communication by pupils in the area of the deaf-blind is lacking. Research might be implemented to understand better the dynamics involved in teaching gross manual signs to the deaf-blind child. We need to know how the psychomotor structures are involved in sending manually expressive signs and in learning to receive them without the benefit of vision. Linguistic studies of the deaf-blind should be included. Studies are needed to describe the contribution of repetition to the acquisition of linguistic skills by the deaf-blind child. It matters little whether those skills are manual or speech. Both skills should lead to communication, independence, and self-expression. A thorough analysis of the method of communication must be understood before whole generations of deaf-blind are taught willy-nilly how to sign without knowing to what degree they comprehend the complexities and power of language. Should we be satisfied with primitive or rudimentary communication skills by the deaf-blind?

Efficiency of Intervention Techniques

While literature is available describing gains by deaf-blind children as the result of specific intervention techniques, few articles examine the effects of discrete techniques in a longitudinal fashion. We suggest that a close, hard, and objective look be taken at the armamentarium of approaches currently in vogue in programs for the deaf-blind (e.g., behavior modification, total communication, Orff-Schulwerk, and sensory stimulation). The outcome of such scrutiny should be a precise definition of each technique's variables which must be considered before any implementation occurs, specification of the circumstances under which such techniques are effective, and especially the relative longevity of training results.

Because of the frequency of stereotypic or self-injurious behaviors (SIB) observed in deaf-blind children, especially those with lower developmental functioning, humane yet effective means of

eliminating or reducing the behaviors have been found to be either (1) ineffective with the deaf-blind child; or (2) contraindicated because of their uncontrolled or undefined side effects. Serious studies to define the parameters of SIB (chart the topography of such behaviors as eye-gouging, biting, and head-banging) are needed. Maladaptive behaviors diminish the amount of time and energy available to the child for more constructive behaviors; and in extreme cases the SIB so mutilates the child that he or she becomes even more handicapped than before, through the loss of residual sight or vision, amputation of fingers, chronic skin conditions, and so forth.

Self-abusive behaviors exhibited by many deaf-blind children might also bear some answers through research conducted with the severely multihandicapped child in state institutions for the mentally retarded. Can the techniques used to control or eliminate negative behaviors for those children be reinterpreted for application with the young deaf-blind child?

Educational research on the deaf-blind child has gone by the wayside for lack of time, interest, money, or a combination of all three. Little real research has been done into the operant conditioning techniques used by individuals in working with deaf-blind children. The application of aversive consequences to stereotypic and other maladaptive behaviors of deaf-blind children has not been clarified, analyzed, or documented.

Save the deaf-blind child from pseudoscientific zeal! The responsibilities of controlling another human being should not be left to an inexperienced, untrained, unknowledgeable individual. The need to know what effective methods are best with a child who is severely handicapped, such as the deaf-blind, has yet to be quantified urgent. Information is urgently needed that will provide data from which we can extrapolate techniques that will lead to more successful teaching, training, or conditioning of the deaf-blind child to permit him or her to function as an independent youth and adult.

The development of any instrument or technique resulting from research should be excluded from the classroom unless a well-trained and experienced individual is present.

On the other hand, we must not shirk our responsibilities to determine which specific approaches are most efficient yet humanizing and what the minimum requirements are that should be established as prerequisites before paraprofessional and even professional staff members are allowed to

design and implement child training programs using such powerfully controlling techniques.

Serious consideration should also be given to the resources developed by professionals in other disciplines (e.g., mental retardation, orthopedics, deafness, blindness, and autism) who have had a number of years of experience collecting information and data. Are techniques of auditory training and language stimulation developed for the deaf also useful with deaf-blind children? Do studies in mobility conducted with blind subjects have direct application to the mobility needs of the deaf-blind child? Seeking answers in the findings of research of other handicaps may not be wise. We do not know whether techniques used with other handicapped children could be applied with success to the deaf-blind child; but efficient cross-applicability cannot be determined without controlled comparative research.

Criterion-Referenced Assessment Techniques

The proliferation of scales, measures, and evaluation instruments evident across the country demands a greater determination of the validity and reliability of the instruments. Special emphasis should be given to ensure that assessment instruments themselves translate easily and clearly to the establishment of valid developmental objectives for each child evaluated. Research defining the varying utility of the different measures and their applicability to program development is sorely needed.

Program evaluation has, at times, been promulgated as scientific research. A rigorous dissection of program effectiveness, including cost benefits and correlative training components and student gains, however, is not often built into the program evaluation model, and post facto observations cannot substitute for a carefully planned and executed program with built-in evaluation and analysis components.

The review of program evaluation reports suggests that most administrators and educational specialists consider reporting a failure of a program design or component something to be avoided at all costs. The field is thus denied information regarding which approaches or models of intervention consistently fail to achieve optimal results. The true test of scientific evaluation of a treatment or technique is always a design which will allow the treatment to fail as well as succeed.

Paraprofessional Rather than Professional Teachers

Limited funding to train and hire professional teachers of the deaf-blind has forced administrators

of programs for the deaf-blind to consider the applicability of paraprofessional teachers in the training of the deaf-blind child. Unfortunately, perceptions of paraprofessional teachers of the deaf-blind are often colored by experiences and observations in other programs. As a result, the administrator may dismiss the value of the paraprofessional teacher as either inconsequential or not worth the staff commitment necessary to ensure effective, economical utilization. Studies of the use of paraprofessionals to supplant rather than to simply supplement professional teachers in a variety of specific techniques should be conducted. If data are available to describe how the administrator can achieve the proper "mix" of teachers and what to expect from various levels of teacher preparation, service programs can more easily and confidently gear up for expanding services.

Conclusion

Research resources are legion. We need only to stimulate, prod, activate, catalyze, and motivate universities or private agencies (e.g., the Rand Corporation) whose resources are geared to research to design, develop, conduct, and coordinate research studies of benefit to deaf-blind children. Following such extensive surveys and analyses of needs (Kakalik and others, 1974), supporting funds should be provided to assist in the implementation of recommendations generated by such analyses.

We should no longer be satisfied with selecting convenient conclusions from our own personal background and training programs as relevant and desirable educational strategies for use with the deaf-blind children today.

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Program Evaluation

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With the advent of criticism of educational programs from outside sources such as Conant and Rickover and the "big business" atmosphere generated by the presence of, and competition for, federal funding, evaluation has become a vital part of the educational system. Procedures for evaluation have taken many forms. The comparison of a student's progress on standardized achievement tests to the national norms has been used as a procedure of program evaluation for many years. The use of outside experts to visit and evaluate the worth of a program has also been very popular. Both of these processes have definite shortcomings as independent tools for program evaluation. Professionals in special education call attention to the dangers of using standardized tests with the students they serve. The friend or foe aspect of outside evaluators contributes to the extreme variability in this method of program evaluation. Certainly more formal procedures are necessary.

This paper deals with the various evaluation prototypes used in general education; those used in evaluation of programs in areas of special education; and those most adaptive to, and currently used in, evaluation of deaf-blind programs.

Evaluation in General Education

In educational programming, evaluation has traditionally been viewed from a negative standpoint. Somehow, the "healthy," self-study aspect of evaluation is the last issue that comes to mind. Instead, professional paranoia is the usual reaction to suggestions of evaluation. Perhaps this is the result of evaluation being recommended or required from outside sources rather than being considered a vital part of the development of a program.

In discussing the topic of education evaluation, House (1971) has stated that "evaluation becomes

desirable when you think you are doing well but feel unappreciated; when you are in serious trouble; or when someone with authority over you insists that you be evaluated." Clearly, evaluation from those supervising can be a very threatening undertaking. Outside pressure groups and parents who are unhappy with the school's product or curriculum also have a definite influence on evaluation procedures.

Many evaluation models have been developed in response to the need for accountability in education. Most of the models appear to be based on five generally accepted models of educational evaluation: Ralph Tyler's evaluation model (1942); the school accreditation model (1960); Robert Stake's countenance model (1967); Daniel Stufflebeaum's context, input, process, product (CIPP) model (1969); and the methodology of evaluation (Scriven, 1967).

The purpose of the earliest reported formal evaluation model (Tyler, 1942) was to measure student progress toward instructional objectives. Teachers and measurement experts specified objectives for their educational programs and developed tests to determine whether these objectives were met. Student progress as ascertained by the testing procedure quantified the success or failure of the educational program. This model tended to foster oversimplification of the school's goals and objectives, and, by measuring only products, certainly ignored the processes of education.

The school accreditation model was developed by the National Study of Secondary School Evaluation in 1960. The purpose of this model was to review the content of, and procedures for, instruction through self-study. The evaluation procedure was developed by committees made up of classroom teachers and administrators. These committees

discussed their educational program and made decisions as to its needs, strengths, and weaknesses. No outside evaluators were needed unless authentication by outside peers was required by higher administration of funding agencies. This model for evaluation tended to increase staff leadership responsibility but was time consuming and generally ignored the value of outside viewpoints.

The countenance model (Stake, 1967) was designed for reporting the ways different groups of people considered the value and content of a program's curriculum. In this model outside groups (Stake used journalists and social psychologists) as well as teachers and administrators were asked for their opinions and judgments about what should be included in a school's curriculum. Through this process evaluators could extract a general view of the program and could gain insight into the conflicting expectations of groups that were affected by the program content. A specific risk in using this model is that value conflicts tend to surface, while the cause of conflicts is generally ignored.

The context, input, process, product (CIPP) model (Stufflebeaum, 1969) was designed to facilitate rational and continued decision making in program evaluation. Stufflebeaum presents four stages of program development and describes the need for assessment or evaluation at each stage. Context evaluations would be determined when a project is being planned. The evaluator would attempt to assess the needs of the proposed program as well as the underlying problems in program development. Input evaluation would provide a description of the capabilities of the program, human and material, to determine whether or not the stated objectives for the program could be met or if the desired activities were feasible. The next step of process evaluation continues through the tenure of the program. Areas of strength or weakness are identified and key events vital to the program are recorded. In product evaluation, the final stage, the determination is made as to whether or not the program related well with its stated objectives and whether the program should be continued, be modified in some direction, or be terminated. For product evaluation, Stufflebeaum suggests the use of a process chart depicting the role of evaluation in educational change. This chart is used to illustrate change, beginning with research and leading through development of the innovative idea, diffusion of information, and adoption of educational change. For each stage of the process, Stuffle-

beaum lists the agency involved, objectives for change, process of change, and criteria level to be reached before moving to the next stage.

Scriven's (1967) lengthy discussion of evaluation deals with the subject from a philosophical standpoint. His concern is the need for evaluation and its formalization from a variety of standpoints, including who should conduct an evaluation and its form. A definitive procedural model like those of the four models previously discussed is not proposed. Scriven does, however, address the various rationales and procedures that are traditionally used in an evaluation process. He makes a strong argument for evaluation as an integral part of a curriculum.

Based on these five models, a host of evaluation designs have been developed for use with specific programs (Atkinson, 1967; Dyer, 1969; Hammond, 1968; Pohland, 1969 and 1970; and Wallace and Shavelson, 1970).

Program Evaluation in Special Education

Little reference to program evaluation in the various areas of special education can be found in the reference literature listed at the conclusion of this paper. Programs that report their evaluation procedures appear to have included them because of federal funding requirements.

The Institute for Development of Educational Auditing reports a study of programs for trainable mentally retarded (TMR) children in Jacksonville, Florida (1972). This study attempts to identify cost factors in the attainment of educational objectives with TMR children. Teachers in the program wrote educational objectives for all students. The teachers also estimated the number of objectives that were achieved by each student. The program administrator reported the total cost of the educational program and the total number of pupils in the program. From these data the average costs per objective and objective achieved per pupil were determined. This system was informative and useful. However, the need for teachers to receive inservice training to write appropriate performance objectives was noted as a definite consideration.

McDonnell and others (1973) described their evaluation procedure for 21 special education programs, funded under Title VI of the Elementary and Secondary Education Act, in Oregon. They used a team of third-party evaluators to comment on program effectiveness. The determination of program effectiveness was based upon the program objectives set by the teacher, the appropriateness of these objectives as judged by the evaluator, and

the degree to which the stated objectives were or were not met. The success or failure of this type of evaluation model would depend greatly on the skills of the teachers in writing appropriate educational objectives and the familiarity of the evaluators with the needs of the students and the limitations of educational intervention in each area of exceptionality.

In evaluating its public school program for gifted children, the state of Illinois (*Annual Gifted Program: Evaluation Report 1972-73*) obtained input from those connected with the program through the use of a rating form. The "Rating Evaluation Form" (1973) was completed by those persons involved in the program, including the teachers, the reimbursement director, the administrator, and parents. Each evaluator was asked to state his or her number of contacts with the program, noting those perceived as most beneficial and those least beneficial. From these data, charts were developed for rating each section of the program. Using the data obtained from this approach, persons responsible for educational programs can get input for evaluation from different points of view, thus obtaining a comprehensive view of program needs and strengths. Schrock (1973) reports a similar approach to evaluating a program for gifted children by means of a checklist evaluation form. This approach certainly may bias the evaluation in favor of the person or persons compiling the rating form.

Moore and others (1973) conducted a lengthy study of preschool programs for hearing impaired children throughout the United States. Their evaluation, however, was based on a comparison of the performance of student groups that received instruction by means of different methods. No evaluation of the educational effectiveness within each program was reported.

Brill (1974) has developed a comprehensive "Self-Evaluation Scale for Residential Schools for the Deaf." In this scale he lists items that are vital to the operation of a residential school, dividing responsibilities into the areas of administration; school organization, including faculty; educational and vocational programs; dormitory life; extracurricular programs; health program; and the maintenance and operations department. This evaluation scale would be useful in identifying areas of need within a residential school program. However, the instrument was not designed to measure program effectiveness, and it could not be used for that purpose.

Proger (1971) calls attention to the confusion in the field of learning disabilities and the need for consistent and formal program evaluation. A case is made against the folly of continued model-building for adaption to each area of exceptionality. Proger suggests the establishment of federally funded, nationwide evaluation centers that would be responsible for the development and administration of an evaluation scheme to be used from the local to the national level.

Rating scales have been used to evaluate student performance and thereby provide certain data related to program evaluation. Balthazar (1972) developed a scale to evaluate the performance behavior of institutionalized mental retardates. Program evaluation procedures used by Balthazar were based on a comparison of two ratings of the population, one at the beginning of the program and the second after a determined period of time. Positive or negative second ratings were used to determine program effectiveness. Programs were redesigned or modified on the basis of data that were obtained in this manner.

Tweedie (1974) modified a scale developed by Curtis and Donlon to rate the behavior of deaf-blind multihandicapped children. Persons who were familiar with deaf-blind children made judgments as to positive or negative behaviors exhibited by a low functioning, deaf-blind child and about the relationships of the behaviors to learning. A determination was made that for an extended period of time (four years), behavioral change could be recorded by means of a videotaping procedure and could be charted to show program effectiveness for an individual student.

Evaluation in Programs for the Deaf-Blind

Evaluation in the area of programs for the deaf-blind has taken a slightly different direction than that taken in either general or special education. Formal models for evaluating programs have not been used extensively. Currently, however, many regional centers are in the process of developing evaluation tools to use throughout the states located within their region. These tools will be used to augment or replace the individualized evaluation procedures currently in use.

In the area of programs for deaf-blind, program evaluation has involved (1) the use of outside experts to visit a program, critique its strengths and weaknesses, and make recommendations for change to the program's administrators; and (2) the use of a teacher-made or standardized rating form designed to chart individual child performance over

a specified length of time. This rating of individual children in programs for the deaf-blind grew out of a mandate from the Bureau of Education for the Handicapped, U.S. Office of Education, Department of Health, Education, and Welfare, stating that "child-by-child" evaluation plans were needed for all the students served by programs using federal funds. Some states also require by law the use of a child-by-child evaluation plan. With this emphasis on individual children, it is understandable that the development of evaluation procedures was influenced to move in this direction.

A notable contribution to evaluation of programs for deaf-blind children has been made by the Teaching Research Division of the Oregon System of Higher Education, working under a subcontract with the Northwest Regional Center for Deaf-Blind. A curriculum based on an individualized evaluation system has been implemented in many of the programs in this region. Developed by Dr. Victor Baldwin and his associates, this program was initially prepared for use with retarded children and has been adapted for use with deaf-blind children. The program is based on taxonomical structure for communication, self-help, and psychomotor skills and includes a set of criteria to determine degree of success on the part of the student. The forms and procedures for recording and aggregating achievement are included so that the system provides a high level of current and cumulative data for each child. A central file is maintained on all students as a means of tracking their progress. Data are available for any desired aggregation; e.g., for an individual student or groups of students or for a single skill or groups of skills. Program personnel, particularly teaching staff, have reacted positively to the utilization of this detailed curriculum and to the evaluation data generated by the system.

While formal evaluation tools, when used, vary to a considerable degree, procedures for evaluation appear to be consistent throughout the regions. Evaluation teams typically visit a program, observe the educational and administrative components, and make verbal and written recommendations concerning their findings.

Regions using outside experts for evaluation vary somewhat in the makeup of their evaluation teams. Numbers of persons on evaluation teams are fairly consistent, usually two to four members. Most of the persons selected for membership on evaluation teams are teachers, administrators, or university professors skilled in the areas of working with the deaf-blind. Occasionally, persons whose

training is in evaluation as a discipline are used as team members or as consultants for the purpose of developing more formalized evaluation procedures. Frequently, a member of the regional center staff serves on the evaluation team. If the region has a person with designated responsibilities in evaluation, that individual usually serves as an evaluator. Many regions also include a person from the program being evaluated and, if possible, a person from outside the region. One region uses a three-member team, with two members being skilled in diagnostics and one as an educational specialist. Another region, using a two-member team, selects an individual who is experienced in education for the deaf-blind and one with experience in program administration and budgeting.

Evaluation procedures of four regional centers will be described to illustrate the various evaluation formats. These four regions are exemplary with respect to the manner in which regions are attempting to formalize their evaluation processes.

New England Region

The New England Region Center has developed a deaf-blind child plan (pages 266–269) that is prepared for each child served within the region. Basically, this phase of the evaluation process consists of a data collection instrument of four sections: a biographical data sheet, a family program data sheet, a baseline data sheet, and a goals and objectives outline to be completed by personnel from the program serving the child. The biographical data sheet is completed when the child enters the program and is updated with information pertinent to the education of that child. The three other sections are completed each year that the child remains in a program within the region. Copies of the child plan are sent yearly to the regional center. In this way program information is obtained on each child in the region.

Southeast Region

Evaluation procedures for the Southeast Region Center are well delineated in the form of guidelines for teams that conduct on-site visits to programs (pages 270 and 271). Two-member evaluation teams visit each federally funded program. On the last day of their visit, they report their recommendations to the persons responsible for the program's administration. Two weeks from that date a written report is sent to the regional center. On the basis of the evaluation teams' recommendations and the written report, decisions are made concerning

program merit and those specific procedures, if any, in need of modification.

The Southeast Region Center is also planning an alternate evaluation procedure. Basically, this alternative procedure would involve selecting students randomly from the deaf-blind registry in various states and evaluating the child-by-child plans completed on each student. These data could then be added to ongoing evaluation information at the local, state, and regional levels.

South Central Region

The South Central Region Center completes a child-by-child evaluation using the *Callier-Azuza Scale* for young children and the "Behavioral Summary" (pages 272-274) for older students in prevocational and vocational programs as one phase of program evaluation. In addition, entire programs are evaluated using the "Goal Attainment Scale" (pages 275-277) an evaluation measure developed by the South Central Region Center. In the use of this instrument, programs are evaluated quarterly in seven areas of concern: medical diagnosis and evaluation; educational assessment and evaluation; child-by-child planning of goals and activities; ancillary services to the educational program, including physical therapy, occupational therapy, and recreational therapy; family services; census information or registry; and continuation of services for each child served by the program. Each area is rated with weighted values from a -2 to a +2. A total score is then obtained quarterly for each program. The "Goal Attainment Scale" is completed by the director of the program being evaluated and by a person from the regional center. Upon completion of the scale, comparisons are made of the two ratings. If differences in ratings are found, these differences generally serve as a basis for further discussion. Rating each program on a quarterly basis provides numerical data illustrative of program achievement in reaching stated goals.

Mountain Plains Region

The Mountain Plains Region Center has a well delineated approach to evaluation using both a child-by-child plan and a program summary report (pages 278 and 279). The components for both the child plan and summary report were the result of input from various teachers, aides, specialists, parents, and administrators in programs for deaf-blind children within the region (Brooks, 1975). In a monograph on the components of an evaluation plan within the region, Brooks (1975) outlined the

development of a state evaluation-planning committee. This committee, made up of persons representing the state, parents, professionals, administration, and teachers, would provide a summary of information about the status of their state's continuum of services for deaf-blind individuals. The target date for the completion of development activities is projected for 1980. Brooks (1975) also provides a proposed planning model illustrating service implementation from direct contact with the child through the state and region to contact with the Bureau of Education for the Handicapped.

The Status of Evaluation Procedures for Programs Serving Deaf-Blind Youth

The variability in the composition of programs serving deaf-blind children has inhibited the identification of any one evaluation procedure as being the correct method. The location of a program (in a school for the deaf, state institution for the mentally retarded, or public school) as well as the number of students served by that program of necessity dictate its resources in terms of personnel and materials available. To demand that all programs regardless of size be evaluated using a standardized instrument could place some at an extreme disadvantage.

The development of evaluation procedures appears to be a high priority in all regional centers serving deaf-blind children. Fair and consistent methods designed to aid and improve services to deaf-blind individuals characterize the goals of these attempts at standardized measures. All the information obtained on the development of evaluation procedures by the regional centers shows concerted effort to provide an improvement in quality of service rather than evaluation for evaluation's sake. A continuation of efforts in this direction over the next several years seems quite likely.

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Deaf-Blind Child Plan

Biographical Data

Note: It is intended that the information contained on this sheet be limited to that which identifies the child and family and/or may be important to the persons writing, reading, or carrying out the goal(s) and objective(s). For in-depth information supporting these comments, refer to the child's file.

			Date submitted _____		
Child's name _____			Agency _____		
Number _____		Street _____	Number _____		Street _____
Town/city _____		State _____	Town/city _____		State _____
		ZIP _____			ZIP _____
D.O.B. _____		Sex _____	Date of admission into deaf-blind program _____		
Etiology: _____					

General statement regarding each of the following: (Use reverse side, if necessary.)

Hearing:

Vision:

Other handicap(s):

Miscellaneous (i.e., medication, physical limitations, allergies, and so forth):

Parent/guardian _____	Address _____
	Number _____ Street _____
Telephone number _____	Town/city _____ State _____ ZIP _____

Pertinent family information:

Deaf-Blind Child Plan

Family Program Data

Date submitted

Child's name

Agency

Family (natural, foster, or guardian) Involvement—(in such areas as training, counseling, respite care, home visits, and so forth). Should no family involvement exist, indicate accordingly.

Deaf-Blind Child Plan

Baseline Data

Date submitted

Child's name

Agency

Developmental Area

Baseline data—(brief statement of present functioning level in this developmental area, including how level was ascertained. In all reporting periods subsequent to the first one, this statement should be related to goal(s) and objective(s) of previous period.)

*Goals and objectives, for our purposes, fall within specific developmental areas—such as (but not limited to) social behavior, self-help, motor, communication, cognitive, academic, vocational, and sensory. Please indicate to which area this sheet applies.

Deaf-Blind Child Plan
Outline of Goals and Objectives

Date submitted

Child's name

Agency

Developmental area _____

Goal(s) and objective(s)—following a brief statement of each goal related to this developmental area, indicate the specific objectives planned to accomplish that goal.

Calendar period (month and year) _____ to _____

*Goals and objectives, for our purposes, fall within specific developmental areas—such as (but not limited to) social behavior, self-help, motor, communication, cognitive, academic, vocational, and sensory. Please indicate to which area this sheet applies.

Guidelines for Site Visit Teams

Identification of Deaf-Blind Children:

1. How many deaf-blind children is the program currently serving?
2. What procedures does the program utilize to obtain the names of potential deaf-blind children?
3. What are the procedures for determining if a child is deaf-blind?
4. What are the procedures for adding a deaf-blind child to the regional register, and what type of information is included on the deaf-blind child and family?
5. What are the procedures for removing a deaf-blind child's name from the regional register in the event of death, movement of the child from the region, and so forth?
6. What procedures does the program have for early recognition of deaf-blind children as soon after birth as possible?

Comprehensive Diagnostic and Evaluative Services:

1. What procedures does the program have for furnishing deaf-blind children and their families initial diagnostic and evaluative services?
2. Do all children receive prompt initial diagnostic and evaluative services?
3. Is the information provided in the diagnostic and evaluative report used to develop an individualized service program for the deaf-blind child and his or her family?
4. What procedures does the program have for systematically reevaluating and modifying individualized service programs for the deaf-blind child and his or her family?
5. Are deaf-blind children receiving reevaluation services on a regularly scheduled basis?
6. Where does a deaf-blind child within this program receive diagnostic and evaluative services and reevaluation services? How far do the deaf-blind child and his or her family travel for such services?

Identification of Resources Available to Deaf-Blind Children:

1. What procedures does the program have for locating and identifying services for deaf-blind children within their immediate area?
2. What procedures are used to notify the regional center of these services and what type of information concerning these services are provided to the regional center?
3. Are these services, once identified, appropriately utilized to provide services for deaf-blind children based upon the individualized service plans?

Programs for Education, Adjustment, and Orientation:

1. How long has the program been in operation?
2. What sources of funds does the program utilize? What are the amounts?
3. Is the program making attempts to secure state, local, and other funds in addition to federal monies?
4. How do sources of funds this year compare to last year?
5. Does the program furnish the regional center with information concerning staff? What type of information is provided?
6. What services does the program provide for inservice education? Does this consist of workshops, seminars, or college courses for credit?

Effective Consultative Services:

1. Are services provided by the program to determine the needs of the families of deaf-blind children? How are these services provided?
2. Are services provided to reevaluate these needs? How are these services provided?
3. Do families of all deaf-blind children receive these services?
4. What procedures does the program utilize to identify and determine the types of services other agencies can provide for the families of deaf-blind children?
5. What procedures does the program have for notifying the regional center of such services, and what type of information is furnished to the regional center?
6. Are these services, once identified, utilized to provide services to the families of deaf-blind children?

Identification of Children Not Served:

1. Have children in the area been identified as deaf-blind who are not currently receiving services?
2. Why are these children not receiving services?
3. What services are needed for these children?
4. What procedures does the program have for notifying the regional center of such cases?

Coordination of All Community Resources:

1. What services are available within an area to refer deaf-blind youths and adults for services? What services are available at the state level, regional level, or national level?
2. Does the program have cooperative work agreements established with other services within the area? How many and with what agencies? Has the program provided the regional center with copies of these cooperative work agreements?
3. What services does the program provide for deaf-blind children who reach twenty-one years of age while in the program?

Dissemination of Information:

1. What procedures does the program have for notifying the public, other local agencies, state, regional and national agencies of the type of services provided deaf-blind children and their families?
2. Does the program furnish information for inclusion in the regional newsletter?

Innovation and/or Demonstration of Services:

1. Has the program developed any new or improved techniques for providing services to deaf-blind children and their families?
2. If so, was the regional center notified?
3. Was this new or improved technique either described in writing or presented at a workshop?

Identification of Federal, State, and Local Resources:

1. Does the program provide the regional center prompt and accurate information of federal, state, local, and other sources of funding utilized in the operation of the program?
2. Does the program furnish the regional center with other types of information needed for program planning and evaluation?

Child-by-Child Plan:

1. Does the program have criteria and procedures established for self-evaluation?
2. Is the regional center provided with appropriate reports?

Research:

1. Is the program currently doing any research?
2. Are areas of research interest identified by the program's staff?

Behavioral Summary

To Be Used with Deaf-Blind Individuals in Prevocational/Vocational Programs

General Information

Agency _____	Client's vision _____
Client's name _____	Client's hearing _____
Date of birth _____	Recorder _____
	Date _____

	None	Poor	Fair	Avg.	Exc.
I. METHOD OF COMMUNICATION					
Sign language _____					
Fingerspelling _____					
Speech (audition or vibration) _____					
Written _____					
Braille _____					
Pictures _____					
II. LANGUAGE					
Receptively understands words or phrases _____					
Expressively uses words or phrases _____					
Receptively understands sentences _____					
Expressively uses sentences _____					
Communicates needs in consistent manner _____					
Understands directions _____					
Carries on discussions _____					
Learns new words or concepts quickly _____					
III. USE OF RESIDUAL VISION (if applicable)					
Eye-hand coordination _____					
Eye-foot coordination _____					
Uses vision to perform work tasks _____					
Uses vision for mobility _____					
IV. MOBILITY					
Gross motor coordination _____					
Fine motor coordination _____					
Explores immediate environment _____					
Mobility on the job _____					
Travels to and from work independently _____					
Uses public transportation _____					
Is a route traveler _____					
Travels independently _____					
Recognizes and reacts properly in emergency situations _____					
V. INDEPENDENT LIVING SKILLS					
Toilet habits _____					
Grooming _____					
Personal hygiene _____					
Ability to select clothing _____					
Ability to maintain clothing _____					
Cooking _____					

	None	Poor	Fair	Avg.	Exc.
V. Independent Living Skills (Continued)					
Ability to maintain living facility_____					
Eating habits and techniques_____					
Ability to use community resources_____					
Ability to shop independently_____					
VI. CONCEPT DEVELOPMENT					
Understanding of money concepts_____					
Ability to manage money_____					
Understanding of time relationships_____					
Knowledge of simple arithmetic_____					
Problem-solving ability_____					
VII. WORK HABITS					
Attendance_____					
Punctuality_____					
Discriminates using all available senses_____					
Ability to organize_____					
Works with minimum of distractibility_____					
Works without constant supervision_____					
Performs sequential tasks after demonstration and modeling_____					
Follows directions_____					
Locates and uses work materials_____					
Understands routine in work situations_____					
Understands changes in work situations_____					
Performs repetitive tasks independently_____					
Adapts to work variation_____					
Transfers learned skills to new tasks_____					
Quantity of work_____					
Quality of work_____					
Consistent rate of speed_____					
Safe work habits_____					
VIII. SOCIAL-EMOTIONAL DEVELOPMENT					
Control of negative behaviors_____					
Acceptance of physical contact and tactile reinforcement_____					
Understanding and acceptance of own capabilities and limitations_____					
Frustration tolerance_____					
Acceptable expression of frustration and anger_____					
Disposition and attitude_____					
Accepts criticism and directions_____					
Selects among alternatives; makes decisions_____					
Willingness to learn_____					
Reliability_____					
Patience_____					
Sense of humor_____					
Self-assertion and competitiveness_____					
Desire for independence_____					
Desire for approval of others_____					

	None	Poor	Fair	Avg.	Exc.
VIII. Social-Emotional Development (Continued)					
Feelings of being a contributing individual _____					
Acceptance of realistic dependency needs _____					
Interacts appropriately with others _____					
Forms friendships _____					
Respect for others _____					

Goal Attainment Scale

GENERAL INFORMATION

Program _____

Person completing form _____

Position in program _____

Date of review _____

SCALE

1st quarter Expected Goal Attainment Score ____; Actual Goal Attainment Score ____

2nd quarter Expected Goal Attainment Score ____; Actual Goal Attainment Score ____

3rd quarter Expected Goal Attainment Score ____; Actual Goal Attainment Score ____

4th quarter Expected Goal Attainment Score ____; Actual Goal Attainment Score ____

Scale contains weighted values from +2 through -2. These are broken down as follows: (+2) best anticipated results, (+1) more than expected level, (0) expected level, (-1) less than expected level, (-2) most unfavorable results.

Goal Attainment Scale (Continued)

Value	Family services	Registry	Continuum of services
-2	Admission interview. Family assessment.	Name and birthdate submitted to regional center.	No information on previous services. No planning for future services.
-1	Admission interview. Family plan. Referral to resources. Social work counseling. Interviews semiannually.	Complete registry form submitted to regional center.	Partial information on previous services and/or plans for future service.
0	Admission interview. Implementation of family plan. Coordination of resources. Social work counseling. Interviews quarterly including home visit. Parent group meeting or workshop semiannually.	Complete registry form submitted to regional center with current information. Ongoing new referrals to regional center on registry form.	Complete information on previous services and plans for future service.
+1	Continued family counseling as indicated. Continued case management. Regular parent group meetings or quarterly workshops. Initiation of parent-action groups.	Registry information updated semiannually. Clarification of incomplete data. Ongoing new referrals to regional center on registry form.	Continuing services during transfer of child from previous to present or future placement.
+2	Continued family counseling as indicated. Continued case management. Regular parent group meetings or workshops. Sibling group meeting semiannually. Social worker as part of the teaching team.	Registry information updated quarterly. Clarification of incomplete data. Ongoing new referrals to regional center on registry form.	Full range of service options outlined and available.

Goal Attainment Scale (Concluded)

Value	Medical diagnosis and evaluation	Educational assessment evaluation	Child-by-child plan	Ancillary services*
-2	Medical diagnosis not current.	<i>Callier-Azusa Scale.</i>	Teacher planning of schedules of activities and materials.	Initial evaluation. No treatment.
-1	Medical diagnosis current. Recommendation made.	<i>Callier-Azusa Scale.</i> Videotape protocol.	Teacher planning of short term goals, activities, and materials.	Evaluation and periodic treatment. No classroom involvement.
0	Medical evaluation and treatment.	<i>Callier-Azusa Scale.</i> Videotape protocol. Summative evaluation quarterly.	Quarterly teacher and aide planning of long- and short-term goals, activities, and materials	Evaluation and periodic treatment. Communication of treatment plans to teachers and aides for classroom carryover.
+1	Medical Plan. Treatment completed. Follow-up on a routine basis.	<i>Callier-Azusa Scale.</i> Videotape protocol. Summative evaluation quarterly. Formative evaluation.	Quarterly teacher and aide planning of long- and short-term goals, activities, and materials. Summative evaluation.	Evaluation and periodic treatment. Communication of treatment plans to teachers and aides for classroom carryover. Periodic consultation visits to classroom.
+2	Medical Plan integrated in total service, educational program.	<i>Callier-Azusa Scale.</i> Videotape protocol. Summative evaluation quarterly. Formative evaluation. Records of informal observation.	Quarterly team planning of long- and short-term goals, activities, and materials. Summative evaluation. Formative evaluation.	Quarterly team planning of child's program and ongoing treatment program with teachers and aides for classroom carryover.

*Physical therapy, occupational therapy, and recreational therapy

Child Plan

- I. Diagnostic staffing outcomes which provide initial and periodically updated information relating to the child's physical, psychological, educational, or social training, and family situation. Functional and prescriptive information should be included when available and appropriate. It was stressed that this information be summarized and expressed in clear, nontechnical language.
- II. Evidence of baseline development for the child which may include the results of initial observations, both at school and at home, and a diagnostic teaching period, the use of developmental scales, and the use of media such as videotaping.
- III. Evidence of the establishment of goals and objectives for the child which result in staff assignments, a schedule of activities, assignment of strategies, techniques, or procedures to be tried, and the equipment and/or materials needed. It is emphasized that this procedure be accomplished by a team effort, the team being comprised of those people who have worked with, or will be working with, the child. This would include family involvement wherever possible.
- IV. Evidence of ongoing "in-house" staffing, comprised of the same team members involved in Part III. This review of the child's status, which would take place routinely—maybe every eight weeks—or whenever special conditions indicate the need, may result in various recommendations, which might include changes in personnel assignment, parent follow-through, increasing or restricting activities, and changes in goals, objectives, and strategies.

Program Summary Report

I. *Brief Program Description*—Include under this section the following:

- A. Name and location of program.
- B. Short description of program, including current personnel, facilities available for children, and status of parent-family involvement in program.

II. *Summary of Child Progress*

- A. Strengths
- B. Constraints

Note: In this section the evidence of child growth as reflected from the various plans will provide the input for some generalized impression.

III. *Program Recommendations*

In this section recommendations would be made for personnel needs which would be strongly supported by the child data available. Such recommendations may be for teacher and/or aides, or they may be for specialist involvement. A rationale should be developed which will show how these personnel requested will respond to individual child plans rather than attempting to justify such requests on the basis of some arbitrary standard.

IV. *Inservice and Consultation*

The implications for this area of recommendation are open-ended. Such recommendations may include the rather obvious need for staff inservice experience or consultation or a need for training physicians to enable them to provide more communicable reports in their diagnostic team involvement. The important input is, as in all parts of the report, that such recommendations be supported by evidence from the child plans.

V. *Physical Space, Equipment, Materials*

In those areas where constraints exist in a given program due to a lack of these components, such recommendations should show how the requested space, equipment, or materials will be used to facilitate the child's goals and objectives.

VI. *Other*

This obviously is a broad category where recommendations may serve to meet the individual needs of children in programs which were not covered in the preceding areas. Some of the things that come to mind include (a) need for equipment maintenance; (b) better nutrition for children and teachers; (c) expanded recreational facilities and/or opportunities for children; and (d) miscellaneous.

Legislation and Legal Action

Frank J. Laski

General Counsel, Massachusetts Department of Mental Health

The purpose of this paper is to offer a description of legislation and legal action as it relates to handicapped persons generally, with a view toward providing some legal perspective to those concerned with rights, protections, services, and programs for the deaf-blind population in the United States. The task poses a dilemma. On the one hand, if we are to consider only those statutes, judicial rulings, and legal administrative processes that specifically pertain to deaf-blind persons, the presentation would be refreshingly brief but totally misleading. On the other hand, if the task is one of surveying all aspects of the state law, federal law, and legal processes that may affect the lives of deaf-blind persons, the result would be an endless but equally useless treatise. Compounding the problem is the huge "future shock" factor acting on the legal rights and responsibilities of handicapped persons. Legal action by and on behalf of handicapped persons in the 1970s is drastically changing relationships with these citizens. Currently, society is in the midst of a transition from the time when handicapped persons were content to rely on special legislative and administrative gratuities to a time when the guarantees of the U.S. Constitution as applied to all citizens through the due process clause and equal protection clause of the Fourteenth Amendment will be fully extended to all handicapped citizens.

Toward presenting an accurate picture of the state of the law as it now affects handicapped persons, this paper includes a description of the selected provisions of state and federal law and an outline and projection of major trends in legal action, with an emphasis on those legal developments that have the greatest potential for impact on the deaf-blind population. Legislation and legal

action in the following basic areas of human need will be dealt with: (1) education and training; (2) rehabilitation; (3) employment; (4) income security; (5) treatment, habilitation, and community services; (6) health care; and (7) mobility and transportation. Separate state statutes, federal laws, and judicial decisions will be related to these substantive areas to develop an overview of (1) the state of the law as it now applies to severely handicapped persons; and (2) the potential of existing laws and developing legal institutions to protect and provide for deaf-blind persons in the years ahead.

Three areas of law of considerable importance to the disabled population of this country are omitted from this paper because they have little impact on the deaf-blind population as a whole. These are (1) criminal law; (2) workers' compensation law and other legal provisions affecting workers who are disabled as a result of work-related accidents; and (3) laws relating to military benefits and protection for disabled veterans.

Before an examination of the seven subareas of legislation and legal action noted above, it may be helpful to consider generally the nature of the legal process and some overall trends in the development of legal rights of the handicapped.

Traditionally, handicapped persons have not had access to legal and political institutions and have made very limited use of the legal process. To understand this isolation, one must have a view of the overall legal process and sources of law.

The legal process may be looked upon as a tripod, the three parts being the legislative process, the judicial process, and the administrative process. The interaction of these three components creates the legal framework both at the state level, to

define our rights and responsibilities as citizens in a particular jurisdiction, and at the federal level, to define our rights and responsibilities as citizens of the United States. A wide range of differences exists in the legal institutions of the 50 states. However, since the New Deal, the interrelationships between the federal and state legal systems are of paramount significance, and most aspects of law and the handicapped are affected by the state legal system and the federal legal system. For example, the most important class of legislation dealt with in this paper is federal-state program legislation. With regard to federal-state programs, both federal and state law together define benefits, determine program availability, and set provider accountability. Usually, authorization, purpose, mandatory rules, and policy are established in federal law. Eligibility, state options, level of benefits, and other terms and conditions are set forth in state law.

While the dynamic interaction of the legislative, judicial, and administrative legal processes is necessary to the development of a sound legal framework for handicapped citizens, advocates of the handicapped have limited their involvement for the most part to "tinkering" with the legislative process. Advocates have worked with the U.S. Congress and state legislatures to achieve specialized benefits and exemptions for handicapped citizens. They have also worked with the Congress to make federal monies available.

Without interpretation by courts and without enforcement through administrative processes, many legislative measures became dead issues. In fact, when one examines the implementation of statutory provisions affecting the handicapped, he or she can readily discern two widely practiced rules of construction that, until recently, have gone unchallenged. First, general laws that are designed to provide benefits and protection to all citizens implicitly exclude handicapped persons. Second, mandatory language in specialized legislation is something less than mandatory when applied to handicapped persons.

Overarching the legal system developed through legislative administrative process are the requirements of the U.S. Constitution. The handicapped person has the same basic rights as other citizens and may invoke the protection of the Constitution to secure due process of law, equal protection of the laws, right to privacy, right to travel, right to association, and religious liberty. Legal theories of due process and equal protection supporting judicial intervention to protect minority groups have

considerable applicability to constitutional rights of handicapped persons, and the further development of these Fourteenth Amendment principles is likely to be the major vehicle by which handicapped persons achieve their appropriate status in society.

Thus, the U.S. Constitution, state constitutions, federal laws, federal and state rules and regulations, federal court action, and state court action all contribute in various ways to make up the legal framework that governs all citizens, including deaf-blind citizens and other handicapped persons. In the following sections, consideration will be given to the influence of these legal mechanisms upon specific life activities of the handicapped.

Education and Training

The most striking and successful examples of the impact of legal action upon the lives of handicapped persons are found in the area of education. Since May, 1972, when a three-judge federal court in Pennsylvania first gave recognition to the concept of equal access to educational opportunity for handicapped children, courts and legislative bodies in almost every state have reaffirmed the constitutional right of all handicapped children to a tax-supported and appropriate education regardless of their physical or mental disabilities.

The case of *Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania* challenged state statutes that were based on the notion that certain children were uneducable (343 F. Supp. 279, 1972). The litigation resulted in a judicially approved consent decree that permanently enjoined Pennsylvania education officials and local school districts from denying or postponing a free public program of education and training to any of the Commonwealth's mentally retarded children.

A few months later a federal court in the case of *Mills v. Board of Education of District of Columbia* (348 F. Supp. 866, 1972) extended the right to education to a class representing all handicapped children in the District of Columbia. The *Mills* plaintiffs were classified as brain damaged, hyperactive, epileptic, mentally retarded, mentally retarded with orthopedic handicap, and, on the basis of these labels, were excluded from District of Columbia educational programs. On behalf of all children who had been excluded or otherwise deprived of access to publicly supported education, the plaintiffs challenged their exclusion and the procedures and practices by which District of Columbia education and social service officials

denied children public education. Basing its decision on the due process and equal protection clauses of the U.S. Constitution, the Mills court ordered that:

No child eligible for a publicly supported education in the District of Columbia public schools shall be excluded from a regular public school assignment by a rule, policy, or practice of the Board of Education of the District of Columbia or its agents unless such child is provided (a) adequate alternative educational services suited to the child's needs, which may include special education or tuition grants, and (b) a constitutionally adequate prior hearing and periodic review of the child's status, progress, and the adequacy of any educational alternative. (348 F. Supp. 866, 1972)

The cases that followed *Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania* and *Mills v. Board of Education of District of Columbia* not only established in many jurisdictions the right to education but also set forth constitutional interpretations of due process and equal protection that have great applicability in terms of protection of handicapped persons in all public human service systems (*LeBanks v. Spears*, 1973). The constitutional doctrine has been best explained by Dimond. He writes:

First, the unjustified exclusion of any child from all public schooling denies to that child the equal protection of the laws when the state makes the opportunity freely available to other children. Second, the operation of our unfair procedure in the stigmatization by public authority of any person or the denial to him of any public good denies the process due each person under the 14th Amendment. Such a stigmatization and denial is involved in labeling children as exceptional, retarded, or handicapped and placing them in a special class, or excluding them from schooling entirely. These two rights, equal protection and due process, merge to form the emerging constitutional right to an education which guarantees to every child a minimally adequate publicly supported educational opportunity (Dimond, 1973).

The above theory has been advanced to establish four major principles (Abeson, 1975):

1. Zero reject education: Access to free public education must be provided for all regardless of degree of exceptionality or fiscal impact on the school system.
2. Normalized education: Education should be provided in the most normal setting consistent with the learning needs of the individual. The presumption is made against segregation; and the preference is for the most integrated, least restrictive environment possible.
3. Appropriate education: Education must be based on an individualized program that is

appropriate to the needs of the particular child and that is subject to periodic review.

4. Due process in education: With respect to placement, reassignment, or other change in the education program of their child, parents are entitled to advance notice of placement and reasons for placement; a hearing by an independent hearing officer, including representation by legal counsel or other advocate; a record of the hearing; the opportunity to inspect records; the opportunity to present evidence; and presentation of an appeal.

Other cases relating to the right to education for handicapped children have successfully attacked the use of culturally biased intelligence tests and other evaluation and testing procedures that adversely affect minority groups and result in inappropriate placement (*Larry P. v. Riles*, 1972).

Aside from the direct consequences of providing access to a great number of children previously excluded from education, the most significant aspect of the right-to-education litigation has been its impact on the legislative process. Prior to *Pennsylvania Association for Retarded Children*, state special education laws allowed for exclusion of certain classes of handicapped children who were deemed unable to profit from school or who were otherwise "uneducable." States with mandatory special education laws failed to implement them or to encourage school districts to end policies of exclusion (Ross, 1972).

After *Pennsylvania Association for Retarded Children*, and other cases, different approaches became evident not only in legislative language but also in seriousness of purpose in implementing mandatory education. Massachusetts, for example, scrapped its many categorical special education programs and, in 1972, enacted a comprehensive special education law that incorporated the zero reject principles and due process rights enunciated in the federal court cases (Hache, 1975). Litigation also speeded action at the federal level.

The influence of right-to-education litigation in reforming federal legislation and policy is reflected in the Education of the Handicapped Act (PL 93-380, 88 Stat., 484) of 1974, which amended the Elementary and Secondary Education Act of 1965. The House Committee on Education and Labor in reporting the amendments noted that:

In recent years federal and state courts . . . have been increasingly upholding the principle that these (handicapped) children are legally and morally entitled to a free appropriate public education. It is to this end that this amendment is addressed for it establishes for the

first time in federal policy that handicapped children are entitled to a free public education (House Report #93-805, 1974).

The amendments, as enacted, incorporated the major principles of the right to education cases, and, through new state plan requirements, tied federal funding for special education to state compliance with due process, zero reject, mainstreaming, and nondiscriminatory testing principles. Specifically, Section 613(a) of the Education of the Handicapped Act requires states to:

Establish a goal of providing full educational opportunities to all handicapped children . . . provides procedures for ensuring that handicapped children and their parents or guardians are guaranteed procedural safeguards in decisions regarding identification, evaluation and educational placement of handicapped children . . . procedures to ensure that, to the maximum extent appropriate, handicapped children, including children in public or private institutions or other care facilities, are educated with children who are not handicapped, and that special classes, separate schooling, or other removal of handicapped children from the regular education environment occurs only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily; and procedures to ensure that testing and evaluation materials and procedures utilized for the purposes of classification and placement of handicapped children will be selected and administered so as not to be racially or culturally discriminatory (PL 93-380).

While the 1974 amendments to the Elementary and Secondary Education Act clearly set federal policy and made available substantial federal resources as financial incentives to ensure equal educational opportunity, the responsibility for providing education to all children rests with state and local school authorities. One should keep in mind that even in areas in which the federal role has included direct support and sponsorship, such as model centers for deaf-blind children, federal programs specialized or otherwise do not supplant state and local responsibility but merely provide one vehicle that may be used to ensure a child's right to education.

Furthermore, although federal funds may have a great influence on the quality of state programs, the existence of federal funding is not a legal *sine qua non* for adequate programs for handicapped children. The statement of the *Mills* court concerning the responsibility of the District of Columbia is applicable to each and every state.

The District of Columbia shall provide to each child of school age a free and suitable publicly supported

education regardless of the degree of the child's mental, physical or emotional disability or impairment. Furthermore, defendants shall not exclude any child resident in the District of Columbia from such publicly supported education on the basis of a claim of insufficient resources (348 F. Supp. 866, 1972).

The implementation of right-to-education laws for severely handicapped children will have ramifications for programs that heretofore may have been recognized as having educational components but were not considered the responsibility of education authorities. First, existing laws and emerging legal theory allow the parent to claim educational services not just for the years of mandatory schooling but at least up to age twenty-one. Second, the courts have universally accepted a definition of education that encompasses the continuing process of developing life skills needed for coping effectively with developmental tasks and demands as well as with environmental tasks and demands (Testimony of Ignacy Goldberg, 1971). This formulation breaks down the distinctions between education and training as they have been applied to exclude preschoolers as well as adolescents and adults from the educational system. Especially important to deaf-blind children and other multihandicapped persons is that skills of daily living, such as toileting, dressing, feeding, personal grooming, and housekeeping and training in mobility and communication, are all appropriate concerns of education.

A broad definition of education also opens up the possibility of compensatory education and higher education for handicapped adults. While the cases to date for the most part have involved elementary school education, other levels of education such as vocational school, college, adult education, and professional education are also equally important. Until recent amendments to the Higher Education Act, the only higher education legislation that explicitly recognized the needs of handicapped persons was the Vocational Education Act. This act, which authorizes federal assistance to ensure that all persons have access to vocational training geared to employment opportunity in their locality, requires some priority for the handicapped. Congress earmarked 10 percent of the federal vocational education allotment for programs serving the handicapped (20 USCA, 1962 [a] [4] [b]). However, despite legislative priority, a recent evaluation of the vocational education program by the General Accounting Office revealed that most states and localities fail to

provide special services for handicapped students. In many states over the past few years, expenditures for handicapped students declined, enrollments declined, and local matching funds for programs for the handicapped became unavailable. Toward remedying the situation, serious consideration is being given to legislative amendments to increase the percentage of federal set-aside monies for the handicapped and stronger requirements to guarantee state and local commitment to programs for the handicapped. Although stronger federal legislation in such areas as vocational education, adult education, and higher education is necessary, it is important to recognize that in these areas, just as in elementary education, the principle of equal protection applies. Where the state has undertaken to provide a certain level of education, the right is one that must be made available to all on equal terms.

As litigation continues with respect to the needs of severely handicapped children, it is likely that the purposes of education and consequently the legal responsibility of educators will be defined to correspond to current federal program purposes for deaf-blind children, to wit: the bringing to bear upon severely handicapped children as early as possible in life specialized professional and allied services to achieve full potential for communication with an adjustment to the world in which they live.

The legal framework now governing the education of handicapped children can be utilized to make available a wide range of services for deaf-blind and other severely handicapped children. In addition, the legal precedents established in the area of education for deaf-blind children can be advanced to secure similar entitlement for deaf-blind adults, especially in the area of vocational services.

Rehabilitation—Vocational Training

While litigation has been the predominant vehicle for legal change in education, legislative action has been the moving force in reform of the rehabilitation system. The vocational rehabilitation program is the oldest cooperative federal-state program providing assistance to handicapped persons. Over the past 50 years, the program has been characterized by growth and expansion. Major amendments to the Vocational Education Act in 1954 and 1968 expanded federal financial support, target population, and scope of services. The Rehabilitation Act of 1973 (PL 93-112, 87 Stat., 394) continued this growth pattern by legislating a

priority for the "most severely handicapped" in the provision of vocational rehabilitation services and adding a new dimension to rehabilitation—due process for rehabilitation clients.

In the area of legal rights of the handicapped, the Rehabilitation Act taken as a whole has the potential of being the most important piece of legislation affecting the handicapped ever enacted by the U.S. Congress. Its importance derives not only from the changes it makes in the rehabilitation programs but also from the civil rights clauses, employment discrimination sections, and architectural barriers enforcement provisions that apply to all handicapped children and adults whether or not they become rehabilitation clients.

The basic vocational rehabilitation program makes available a wide spectrum of services to disabled clients who have a substantial handicap to employment and who may reasonably expect to benefit from services in terms of employability. The vocational focus has always been the hallmark of the rehabilitation program. However, in recent years the concept of employability has been broadened, and the Congress has made moves to reduce the emphasis on gainful employment and vocational goals. A key element of the program is the vocational rehabilitation counselor, who acts as a counselor-broker for the disabled person. He or she verifies eligibility on the basis of a finding of physical or mental disability, assists in planning the individualized program for the client, and acts as broker to purchase and arrange services necessary to carry out the program. Under the law the counselor can tap a wide array of services, including physical and mental restoration services; vocational and other training services; placement and postemployment services; counseling and guidance services; telecommunications services; sensory and other technological aids and devices; interpreter services for the deaf; reader services, orientation, and mobility services for the blind; and any other goods and services "which can reasonably be expected to benefit a handicapped person in terms of his employability" (29 USCA, Section 723).

As one can see, the client through his or her counselor can obtain all necessary services, whether they be medical or medically related services, social services, or education and training services, to complete his or her rehabilitation program. This flexibility, while necessary to develop a program to fit the needs of the client, does allow for the exercise of a great deal of power and discretion by the counselor in arranging services and carrying out multiple tasks that many disabled persons could

not accomplish independently. This power plus the discretionary nature of the eligibility determination process and its potential for abuse led to demands by disabled persons for more client participation in programs and more counselor and state agency accountability. Congress responded with Section 102 of the Rehabilitation Act of 1973, which not only brings due process to rehabilitation but also may have the potential for changing the nature of the entitlement to rehabilitation services for the most severely disabled.

Section 102 provides for the mechanism most essential to due process in any service-delivery setting—the individualized plan. It requires that the counselor and client develop jointly an individualized, written rehabilitation program that includes the terms, conditions, rights, and remedies for provision of services. Essential elements of the written program are long-range and intermediate rehabilitation goals, statement of specific services to be provided, timelines for provision of services, objective criteria and processes for program evaluation, and notice of availability of client-assistance projects. The law also sets forth requirements for annual review and modification of the client program, specifies procedural guidelines for terminating service, and establishes a strict standard for finding ineligibility for service (29 USCA, Section 722).

Any decision on termination of a disabled client must be made only with full participation of the client and his or her parent or guardian; and the rationale for the decision must be recorded in the written plan, with a certification that the provision of services has demonstrated beyond a reasonable doubt that the individual is not capable of achieving a vocational goal, such decision and certification being subject to annual review with full consultation and participation by the client (29 USCA, Section 722(c)). These and other procedural rights, when coupled with other legal requirements concerning the order of selection for services and the mandated priority to serve the most severely handicapped individuals, give to multi-handicapped individuals who may require long-term services to realize their vocational potential new opportunities to access the services that they need through exercising their rights under the federal-state rehabilitation program. The legal rights embodied in the individualized program provisions cannot be underestimated. The law now imposes a new degree of accountability for counselor action and agency decisions. In fact, it may be persuasively argued that the Rehabilitation Act of 1973 (as amended by the Rehabilitation

Amendments of 1974) establishes rehabilitation as an entitlement by providing the legal framework for a contractual basis for the provision of rehabilitation services.

Ideas of client contracts for services and client participation in program planning raise complex legal and policy questions when applied to deaf-blind clients or other clients with whom counselors and providers may not be able to communicate readily. Those questions arise not only with regard to rehabilitation but also with respect to education, employment, and other areas in which due process becomes an integral part of programs for the handicapped. The issue of client advocacy and client representation will be addressed later in this paper. Suffice to say that in rehabilitation, client assistance, advocacy, and legal representation are being advanced through a series of special client assistance projects in which are being explored various ways to ensure that independent advocates are available to help clients exercise their rights and available to assist them in negotiating the vocational rehabilitation service system.

The development of new client-advocate-counselor-provider relationships will, to a large extent, influence the degree to which legal rights and entitlements are actually realized by disabled persons who need rehabilitation services.

In addition to reforms in the basic federal-state rehabilitation programs, the Rehabilitation Act of 1973 contains a number of provisions, in titles IV and V of the act, that give handicapped persons and their advocates new mechanisms to assert rights to employment and access to transportation and public buildings. The most far-reaching provision is the civil rights clause of the act (Section 504), which includes the following:

No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of this handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

The language and legislative history of the Rehabilitation Act of 1973 make clear that the foregoing section was patterned after Section 601 of the Civil Rights Act of 1964, which prohibits discrimination on the basis of race, color, or national origin, and Section 901 of the Education Amendments of 1972, which relate to sex discrimination. Section 504 of the amendments establishes the federal policy that all programs receiving federal financial assistance shall be operated without discrimination on the basis of handicap. As indicated by a report of the Senate Committee on

Labor and Public Welfare, Section 504 was intended to protect all handicapped persons in relation to federal assistance in employment, housing, transportation, health services, and other federally aided programs. Among the examples of protected persons, the committee cited:

... physically or mentally handicapped children who may be denied admission to federally-supported school systems on the basis of their handicap; handicapped persons who may be denied admission to federally-assisted nursing homes on the basis of their handicap; those persons whose handicap is so severe that employment is not feasible but who may be denied the benefits of a whole range of federal programs; and those persons whose vocational rehabilitation is complete but who may nevertheless be discriminated against in certain federally-assisted activities (Senate Report No. 1139).

Clearly, all deaf-blind persons, in pursuing many life activities and in relating to service providers, will be able to invoke the protection of Section 504.

The Office of Civil Rights of the U.S. Department of Health, Education, and Welfare and other federal agencies are now working on the implementation and enforcement of Section 504. Congress intends a compliance program that is similar to those developed for racial and sex discrimination, including where necessary the imposition of sanctions, such as the termination of federal financial assistance, against those who discriminate against deaf-blind and other handicapped persons. While the withholding of federal monies from school systems, housing authorities, and other public and nonprofit entities should stimulate the quick development of nondiscriminatory practices, the handicapped need not rely on federal enforcement to secure rights under Section 504. On the basis of experience under the Civil Rights Act of 1964, the prohibition against discrimination on the basis of handicap may be enforced through federal court action on behalf of individual handicapped persons who have been subject to unlawful discrimination. Court actions based on Section 504 have already been brought to secure rights in education (*North Carolina Association for Retarded Children v. North Carolina*, 1972) and in transportation (*Disabled in Action v. Hughes, et al.*, 1974); and the argument that Section 504 gives handicapped persons standing to bring suit to enjoin discrimination has much support in past federal court rulings. For example, in granting a private right of action under Section 601 of the Civil Rights Act, the U.S. Court of Appeals for the Fifth Circuit concluded:

The section is a prohibition, not an admonition. In the absence of a procedure through which the individuals

protected by Section 601's prohibition may assert their rights under it, violations of the law are cognizable by the courts. The Bossier Parish School Board accepted federal financial assistance in November, 1964, and thereby brought its school system within the class of programs subject to the Section 601 prohibition against discrimination. The Negro school children, as beneficiaries of the Act, have standing to assert their section 601 rights (*Lemon v. Bossier Parish School Board*, 1971).

The analogy is sound. Simply substitute Section 504 for Section 601 and *handicapped persons* for *Negro school children* and the potential for legal action of the same magnitude as has taken place on behalf of other minority groups becomes evident with regard to handicapped persons.

Employment

Expansion of vocational rehabilitation programs and improved educational opportunities are both essential to the achievement of equal employment opportunity for handicapped persons. Just as essential, however, is the legal framework that governs the employment relationships of handicapped persons.

Smith (1974) has outlined the range of vocational potential for deaf-blind persons (which could be applied also to other severely handicapped persons) as being from highly supervised, nonproductive sheltered work to advanced skill-trades and professional employment. The present legal framework deals in some respects with this entire spectrum of vocational effort of handicapped persons. Three major types of laws are relevant:

1. Laws that secure equal access and opportunity for handicapped persons in the competitive labor market
2. Laws that provide some protection for handicapped workers through supported or subsidized work or through legal incentives to hire handicapped persons
3. Laws that regulate noncompetitive employment and work activities of handicapped persons in sheltered settings

Some laws that deal with the employment relationship serve more than one of the purposes mentioned above. However, a close examination of the laws indicates a preoccupation with access to the competitive labor market and retention of gainful employment and much less concern for those citizens whose disability may preclude competitive employment.

The major focus of legal action by minority groups excluded from the labor market has been on enactment and enforcement of the antidiscrimi-

nation statutes at the state and federal level. Since the close of World War II, most states have enacted fair employment practices acts to prohibit discrimination on the basis of race; creed; national origin; and, more recently, sex and age. The enactment of the Civil Rights Act of 1964 and the creation of the Equal Employment Opportunities Commission at the federal level gave a great deal of impetus to equal employment opportunity at all levels. During the last few years many states have extended the coverage of their fair employment laws to the physically and mentally handicapped (*Employment Rights of the Handicapped*, 1974). Typically, these statutes make it unlawful for any employer to refuse to hire or to discriminate against an employee or job applicant on the basis of disability if the disabled person is otherwise qualified (*Nevada Fair Employment Practices Act*, 1973).

Discriminatory practices are defined in various ways under the different state fair employment practices laws. One method derived from Title VII of the Civil Rights Act is the use of language "bona fide occupational qualification" (BFOQ) to establish exceptions to what would otherwise be a discriminatory practice. The meaning of BFOQ is well defined under the federal law with respect to religion, sex, and national origin. For example, it is permissible to hire only the members of a particular religion to serve as minister, but it is impermissible to hire only women as airline flight attendants. The BFOQ exception with respect to the handicapped, however, is not well defined, and there is little case or administrative law that provides an interpretation. Good hearing may be a BFOQ for certain jobs such as a telephone operator or policeman, but it would not be a BFOQ for other positions such as a postal worker or accountant. Similarly, other disabilities such as blindness, mental retardation, paraplegia, and quadriplegia may or may not affect BFOQs. Development of criteria for bona fide occupational qualifications should be based on the demonstrated ability of handicapped persons to perform a wide variety of jobs in various work settings in public employment and private industry. One example of employment performance is found in the record of severely handicapped persons in federal service. Since 1964, over 2,000 persons have been employed through the United States Civil Service Commission's special appointing authority for job applicants with severe physical handicaps. Handicapped persons have been employed by over 30 agencies in all the 50 states. Employees include blind computer operators and carpenters' helpers; paraplegic radio repairpersons and clerk typists; deaf postpersons

and taxpayer representatives; and persons representing nearly 200 additional job titles. During the first eight years of the program, the severely handicapped employees compiled excellent work records, with less than 1 percent of all appointees terminated for cause or other involuntary reason (*U.S. Civil Service Commission*, 1973).

To date, only a small number of cases have been brought by handicapped persons under fair employment practices acts. However, evidence of effective enforcement does exist in some states. For example, in Connecticut a complaint was filed under that state's fair employment practices law by an individual who was confined to a wheelchair and denied a job as a packer in an industrial plant. The job consisted of taking muffler clamps from a bin, putting them into a small box, taping the box, putting the small box into a larger box, taping the larger box, and then putting it onto a skid. Most of the job could be performed while seated, and the complainant felt that he could perform the required tasks. After an investigation by the Connecticut Commission of Human Rights and Opportunities, the employer capitulated and agreed to hire the complainant, pay back wages, and accommodate him by lowering a tape machine and moving a skid (Walther, 1974).

Those legal provisions that require employers to take affirmative action to hire and promote minority groups, including the handicapped, are a step beyond antidiscrimination laws. An example is Section 503 of the Rehabilitation Act of 1973, which requires federal contractors with public contracts in excess of \$2,500 to take affirmative action to employ and advance in employment qualified handicapped individuals (29 USCA, Section 793). The United States Department of Labor has promulgated regulations that prohibit discriminatory practices in employment of handicapped persons and that set forth the affirmative action clauses required in federal contracts (39 Fed. Reg., 1974). Current enforcement efforts seem to focus on active recruitment, advertising of policies of nondiscrimination, and attempts to eliminate negative attitudes of employers and employees. However, the reach of affirmative action could easily extend to modification of the work setting, provision of additional communication modes, and restructuring of job tasks for handicapped persons or even establishment of goals for the employment of severely handicapped persons.

One should note that the procedures that are being developed under affirmative action legislation may not only supplement but also may quickly supplant the traditional special placement

approaches such as those authorized by the Employment Services Act (29 USCA, Section 49). These approaches, which emphasized employee counseling and employer acceptance rather than employee preference and employer compliance, have proven to be markedly ineffective since the creation of the federally supported, state-operated employment security system in the 1930s.

Despite the potential of provisions designed to ensure equal employment opportunity, a need exists for legal mechanisms to establish special preferences for handicapped persons and to form the legal foundation for a broad range of supported work, including sheltered work activities. The current legal provisions that deal with these issues for the severely disabled population authorize small categorical programs. In comparison with the quota provisions, direct subsidies, and other incentives that are provided in European nations, programs in the U.S. are quite limited in scope.

Two acts that provide for categorical support work programs are the Randolph-Sheppard Act (20 USC, Section 107) and the Wagner O'Day Act (41 USC, Section 46). The former establishes a preference for blind persons in the operation of vending stands in federal buildings. The purposes of the act are to provide remunerative employment to blind persons and to enlarge economic opportunities for the blind. Approximately 3,500 blind persons participate, with an average net income of about \$7,000 in 1972. While the objective of the act is self-support for those blind persons, the reservation of the federal vending stand market to a single disability group clearly establishes the noncompetitive nature of the employment.

In enacting recent amendments to the Randolph-Sheppard Act, the Congress made a number of findings, including (1) failure in the development aspect of the program; (2) potential to double the number of licenses for the blind within five years; and (3) a need for uniform treatment of blind vendors, establishment of guidelines for operation of state programs, and administrative and judicial procedures to ensure fair treatment of vendors (Randolph-Sheppard Act Amendments, 1974).

The Wagner O'Day Act, which was originally passed in 1938, also established supported work for blind persons by creating a mechanism by which sale of certain designated commodities and services to the federal government would be reserved for the blind. In 1972 the act was amended to cover not only the blind but also other individuals who have physical or mental disabilities

that are of such a nature as to prevent them from engaging in competitive employment (USC, Section 48(b)). Thus, workshops for cerebral palsied persons, mentally retarded persons, and others may now receive support through preferential federal contracts.

A more normalized approach to federal support for employment of the type fostered by the Randolph-Sheppard Act and the Wagner O'Day Act is exemplified by recent amendments to the Small Business Act, which authorizes provision of long-term credit and equity capital and other assistance to handicapped individuals or organizations assisting such individuals in obtaining financing in connection with purchase of a small business concern (15 USCA, Section 636(h)).

Except for some minor preferences in civil service employment (counterpart vending stand legislation), legal provisions for supported work at the state level are rare. The recently enacted employment program in Massachusetts is an exception to the rule of the state legislative vacuum in this issue (Mass. Gen. Laws, 1973).

In terms of noncompetitive employment for handicapped persons, the current legal structure relies heavily on regulation and adjustment of wage levels for handicapped persons. Both the federal Fair Labor Standards Act (FLSA) and its state counterpart provide for the employment of handicapped workers at wages lower than the minimum wage. The FLSA sets a floor of 50 percent of the minimum wage and provides that wages paid shall be commensurate with wages paid to nonhandicapped workers for essentially the same type, quality, and quantity of work. The Secretary of Labor, however, may issue special certificates for employment at wages that are less than 50 percent of the minimum wage and that are in proportion to the worker's productivity, where the work is incidental to a training or evaluation program (FLSA, 29 USCA, Section 214).

The Secretary of Labor is also authorized to establish special rates of compensation for handicapped workers who are employed in work activity centers that are designed exclusively for workers whose physical or mental handicap is so severe as to make their productive capacity inconsequential.

The specialized provisions in the minimum wage law not only serve the purpose of creating employment opportunities for handicapped persons but also prevent exploitation of handicapped persons by regulating conditions for exceptions to the minimum wage. In the case of *Souder v. Brennan* (362 F. Supp., 1973) the federal district court

declared that the FLSA is applicable to patient and resident workers in state hospitals and institutions for the mentally ill and mentally retarded. The defendant Secretary of Labor was ordered to initiate enforcement activities to halt peonage practices that were and are yet prevalent in large residential institutions.

Recently, the Department of Labor has promulgated regulations that provide for payment of less than the minimum wage only in limited situations (e.g., training and evaluation) and that extend to patient-laborers many of the same safeguards available to sheltered workshop clients (40 Fed. Reg., 1975).

A number of actions are now pending in federal and state courts concerning the implementation of the minimum wage provisions and the payment of back wages and damages to patient-laborers (*Jortburg v. U.S. Department of Labor*, 1974).

Income Security

Minimum levels of income security for the financially needy have, over the last few decades, been provided under the public assistance titles of the Social Security Act (42 USC, sections 401-410). These titles established programs and grants from the federal government to the states. States maintained responsibility for operating programs for the aged, the blind, the disabled, and the dependent children under minimal federal standards. Each state set eligibility requirements and level of payment. The only major exception to this pattern prior to 1972 was the childhood and worker disability provision under Title II of the Social Security Act (42 USC, Section 202(d)). As part of the social security system's objective to provide insurance coverage for reduction of a worker's income due to disability, death, or retirement, the Congress in 1957 authorized benefit payments to adult disabled children. Under the childhood disability provisions, a disabled person eighteen or older who has been disabled prior to his or her twenty-second birthday and who is the child of a retired, deceased, or disabled worker may receive monthly social security payments. While this program actually affected few handicapped children and the benefit payments were small, the Title II program served in many ways as the model for the federalization of three public assistance titles under the Supplementary Security Income program (SSI), which became effective in January, 1974 (PL 92-603).

The new combined Supplementary Security Income program providing aid to the aged, blind,

and disabled is important to handicapped persons in a number of respects. First, it eliminates the age restriction contained in the former Aid to the Blind and Aid to Disabled programs, which for the most part did not aid persons under eighteen years of age. By allowing a blind or otherwise disabled child to qualify for payments on his or her own, the program recognizes the increased cost of raising a handicapped child and enhances the ability of the low income family to maintain the child at home.

Second, the SSI program provides a definition of disability that is similar to the Title II definition and that can be applied uniformly in all states in disability determination (42 USCA, Section 1614). In the same manner, federalization allows for uniformity in other aspects of eligibility and will eliminate many state policies that discriminate against families with handicapped members. For example, parental responsibility for adult handicapped children was formerly required in many states but is now eliminated.

Third, and perhaps most importantly, eligibility for SSI tied the disabled person into eligibility for a variety of health and social services. For example, medical care under Title XIX of the Social Security Act, social services, and vocational rehabilitation services are 100 percent reimbursed by the federal government.

The SSI program is new, and a number of adjustments in policy and administration must be made. Legal action by disabled persons and their advocates will probably follow the litigation patterns that were most common under the old social security programs. However, federalization has eliminated many of the inequities in payment level and eligibility requirements that existed in the old state-run programs. With minor modifications the system of income security for blind and severely disabled children and adults can be expected to provide much needed support in the areas of necessities of daily living.

The only other federal provision that directly affects income payments to disabled persons is that section of the Internal Revenue Code that allows for an additional tax exemption for a blind taxpayer or his or her spouse (26 USCA, Section 151(d)). The exemption may be considered a form of financial assistance. Many state tax codes have analogous provisions as well as exemptions, rebates, and preferences on other state taxes, rebates, and fees. These provisions benefit the blind to a much greater extent than other disabled citizens.

Treatment—Habilitation and Community Services

Legal action challenging the confinement of civilly committed mentally ill patients has solidly established constitutional rights to treatment and habilitation for certain groups of handicapped citizens and is leading to the establishment of affirmative rights to services in the community. In cases of confinement of the mentally ill and mentally retarded, courts have held that when the reason for committing an individual to a facility is treatment or habilitation, then treatment or habilitation must be provided (*Jackson v. Indiana*, 1972). While the right-to-treatment cases directly attack the conditions in grossly substandard institutions for the mentally disabled, the legal principles may be applied to address conditions in any residential setting that restricts the personal liberty of residents.

The rights recognized in the treatment cases are especially relevant to deaf-blind persons and should be applied toward the following ends:

1. To secure and protect the rights of those deaf-blind persons who are being discovered in increasing numbers residing in institutions for the retarded.
2. To define the rights of those deaf-blind persons whose level of functioning renders them highly dependent on others and requires some form of lifelong care and supervision
3. To elaborate on the legal principle of least restrictive alternative as it applies to the deaf-blind person

The leading judicial opinion establishing the clear constitutional basis for a right to treatment for mentally disabled persons in Federal District Judge Johnson's opinion is *Wyatt v. Stickney*, which was recently affirmed by the U.S. Court of Appeals for the Fifth Circuit (503 F. 2nd 1305, 1974). The federal district court decision applied the right to treatment to all mentally ill and mentally retarded persons confined in public institutions in Alabama.

In regard to the mentally ill, Judge Johnson stated that committed patients "unquestionably have a constitutional right to receive such individual treatment as will give each of them a realistic opportunity to be cured or to improve his or her mental condition" (344 F. Supp. 373, 1972).

As to the residents of Partlow State School, it was held that "the mentally retarded have a constitutional right to receive such individual habilitation as will give each of them a realistic opportunity to lead a more useful and meaningful

life and to return to society" (344 F. Supp. 387, 1972).

Initially, the court ordered Alabama to develop a plan for treatment and habilitation. However, further relief was required by the state's failure to improve the conditions that expert testimony had shown to be inhumane and devastating to residents—conditions that were characterized by lack of safety, lack of privacy, malnutrition, exploitation of patient labor, solitary confinement, excessive use of restraints, inadequate staffing, lack of individualized programs, deterioration of physical and mental conditions, brutality, and patient deaths. Therefore, to rectify these conditions and implement the right to treatment, the Wyatt court order not only set down the general parameters of minimum treatment (i.e., a humane psychological and physical environment, a qualified staff in numbers sufficient to administer adequate treatment, and individualized treatment plans) but also set forth in detail the minimum constitutional standards for adequate habilitation of the mentally retarded and for adequate treatment of the mentally ill. To monitor implementation and guarantee that residents are afforded constitutional and humane treatment, the court directed the establishment of a human rights committee and retained jurisdiction of the cases.

The Governor of Alabama and the Mental Health Board appealed Judge Johnson's decision. Since the existence of a judicially enforceable right to treatment was rejected by another federal court in *Burnham v. Department of Public Health of Georgia* (329 F. Supp. 1335, 1972), Wyatt and Burnham were joined on appeal. In their appeal Governor Wallace and the Mental Health Board contended inter alia that:

1. The district court erred in holding that the patients and residents have a constitutional right to treatment.
2. The right to treatment and habilitation is not susceptible to determination by judicially ascertainable and manageable standards.
3. The right to treatment involves heavy expenditures of funds, and therefore the court's decision invaded an area of decision making reserved exclusively to the state legislature.

Relying heavily on its recent decision in *Donaldson v. O'Connor* (493 F. 2nd 507, 1974), the U.S. Court of Appeals for the Fifth Circuit rejected each of these arguments. Reviewing the holding in *Donaldson*, Judge Wisdom noted:

We held that where the justification for commitment was treatment, it offended the fundamentals of due process if treatment were not in fact provided.

Our express holding in *Donaldson* and here rests on the *quid pro quo* concept of rehabilitative treatment or, where rehabilitation is impossible, minimally adequate habilitation and care (503 F. 2d 1305, at 1314).

On the basis of evidence that there was substantial agreement among professionals as to standards of treatment and habilitation, the court reaffirmed that the right to treatment could be implemented through judicially manageable standards. On the question of judicial usurpation of the legislative prerogative of allocating resources, the court cited a long line of precedents (in the juvenile field, in the area of adult corrections, and in other areas) that firmly establish that while state legislatures are free to determine policy and funding for social services, the legislatures cannot for budgetary or other reasons provide those services in a way that will result in a denial of constitutional rights. Quoting Supreme Court Justice Harry A. Blackmun, the court emphasized: "Humane considerations and constitutional requirements are not in this day, to be measured or limited by dollar considerations" (503 F. 2d 1305 at 1315).

One aspect of the fifth circuit court's decision in *Wyatt* that served to clarify the constitutional basis of right to treatment deserves special attention for its implications for care for deaf-blind persons. In challenging the right to treatment, Governor Wallace, attempting to justify commitment and restrictions on mentally disabled persons on the basis that they were unable to care for themselves, claimed that custodial care in and of itself met an important state interest inasmuch as it relieved families and friends of the burden imposed upon them by the disabled. In rejecting this reasoning, the court found that not even minimally adequate custody was being provided in Alabama institutions. Furthermore, the court explicitly found that the need to relieve families, friends, or guardians of the burdens of care could not in any way justify the massive curtailments of individual liberties that the disabled had undergone.

While there is no state statute that authorizes involuntary commitment of a physically handicapped person solely because he or she is in need of care, the Governor's assertion in court that the families of the disabled are the "true clients of the institutional system" could also be made concerning institutional and long-term care of the multi-handicapped. Many custody and care arrangements while as a matter of law are voluntary and

consensual are in fact nonvoluntary and programmed for the benefit of the family rather than made in the best interests of the disabled family member.

In the case of many deaf-blind children, there is no question that their care and training place considerable demands and long-term pressures on families; and, as Smith (1974) suggests, there must be some recognition that facilities and resources apart from the family must be available to share the responsibility for dependent deaf-blind persons. The need and extent for third-party (presumably public) intervention on behalf of deaf-blind persons and other developmentally disabled persons is of course distinguishable from the need for intervention on behalf of the mentally ill and their families. In the case of the latter, the illness may be short term and the impact on family life temporary. A great range of treatment options may be available in the community. In addition, the tension and strain on the family unit may be relieved in many ways that impose little if any restrictions on personal liberty (e.g., separate living arrangements). On the other hand, the low functioning deaf-blind person will require care and supervision throughout life, and the family unit must constantly adjust to the needs of the disabled family member and must interact with a number of professional care givers.

The differences cited above may lead one to dismiss Judge Wisdom's rejection (or at least drastic limitation) of the *parens patriae* rationale for state custody as unwarranted and clearly not applicable to developmentally disabled persons. However, if the court's decision is interpreted as a judicial reinforcement that *parens patriae* cannot be invoked on the basis of the best interests of family members or other third parties, then it clearly provides a valuable safeguard in evaluating care and residential arrangements for deaf-blind and other persons. Furthermore, it would seem that the necessary implication of the court's holding, specifying that state intervention must be based on the provision of treatment not custody, is that, in the case of deaf-blind and other developmentally disabled persons, once the state intervenes, it has a continuing obligation and affirmative duty to provide those services necessary for the person to reach his or her developmental potential.

Along with the duty of treatment imposed by *Wyatt* and *Donaldson*, one should note the state's use of police power (i.e., the power to protect the public health, safety, welfare, and morals) to intervene in the lives of the mentally disabled has

been severely limited both by statute and by cases such as *Lessard v. Schmidt* (1972) that place upon the state a strong burden of proof as to dangerousness to others in order to justify police power commitments. This burden will rarely, if ever, be met for developmentally disabled persons, which leaves open the *parens patriae* basis for intervention; i.e., the state must justify that intervention is in the best interests of an individual who lacks the capacity to make decisions concerning his or her care, treatment, and habilitation.

Legal action is not only firmly establishing affirmative rights to treatment and habilitation but is also encouraging treatment and habilitation in the community and under the most normalized conditions possible. The legal principle that comes into play is the right to least restrictive alternative. Generally stated, this principle holds that where governmental activity leads to regulation adversely affecting constitutionally protected activities or constitutionally preferred groups, there is an obligation to explore and employ other possibilities for accomplishing governmental purposes through means least restrictive to personal liberties (*Shelton v. Tucker*, 1964).

Chambers (1972) has developed the legal thesis for least restrictive alternative as applied to civil commitment of mentally ill and mentally retarded persons; and the doctrine has been specifically approved by federal courts in *Wyatt*, *Welsh v. Likins*, and *Lessard v. Schmidt*. The principle applies not only to issues of commitment and discharge but also to modality of care and treatment. In *Wyatt v. Stickney* the court stated that the residents of Partlow State School "have a right to the least restrictive conditions necessary to achieve the purposes of habilitation." The court also ruled that no retarded person could be admitted to the institution if adequate community services were available for that person and that the institution was to make efforts to place residents in smaller, less structured settings and to integrate residents into the community.

In declaring a right to least restrictive alternative, the court in *Welsh* also declared an affirmative duty on the part of the state to develop and provide appropriate alternative community services.

In his decision of October, 1974, Judge Larson ordered the defendants to devise a written plan to provide community placements for all institutionalized residents capable of placement. The plan must specifically consider methods by which severely and profoundly retarded persons can be

placed in community facilities equivalent or superior to the institution (*Welsh v. Likins*, 1974).

The issue now is not so much the existence of a right to services in the community, but how litigants can enforce the right and how quickly states will implement it.

Health Care

Legal entitlements to health care are interwoven with many of the legal claims already discussed. For example, the issue of the adequacy of medical services arises in court actions on right to treatment and habilitation. Physical restoration and other medically related services form a large component of rehabilitation services. In some legal contexts (e.g., tax laws and military medical assistance), the lines between educational services and medical services are blurred (*Welsh v. Secretary of Defense*, 1974). However, the major legal provisions that affect medical care for disabled persons under sixty-five are found in two titles of the Social Security Act—Title XIX, "Medical Assistance" (42 USC, Section 1396), and Title V, "Maternal and Child Health and Crippled Children Services" (42 USC, Section 701).

Medicaid, under Title XIX, is a cooperative federal-state program for financing medical care for the indigent and near indigent. It is a welfare-based program that is administered by the states through a vendor payments system with federal reimbursement for expenditures. Federal cost sharing varies from 50 to 83 percent, depending on the per capita income in the state. Eligibility to participate in Medicaid varies from state to state as do the services that are provided. All states must provide coverage to all persons who qualify for categorical assistance and almost all Supplementary Security Income beneficiaries. In addition, states may choose to include those who are medically needy, i.e., with incomes too high to qualify for money payments but not high enough to meet medical needs. The mandatory package of services that a state must provide under Title XIX for SSI and AFDC recipients includes: inpatient hospital services; outpatient hospital services; laboratory and X-ray services; physician services; skilled nursing home services for those over twenty-one; early periodic screening, diagnosis, and treatment services for children; home health services; and family planning services. In addition, a state may include a wide range of optional services and items. Among those that would be of benefit to the deaf-blind population are speech and audiology services, physical and occupational therapy, hearing aids,

skilled nursing for children, and intermediate care facility services.

Early periodic screening, diagnosis, and treatment of children (EPSDT) is a mandatory service under Title XIX that has been given priority attention by the federal government. In 1971 the Department of Health, Education, and Welfare issued regulations requiring states to conduct outreach programs to provide health screening and treatment to all children. This included referral of children for treatment. Because of the potential cost of the EPSDT program, a number of states have been reluctant to implement it. However, federal court suits have been brought to force states to provide early screening, and at least one lower court decision requiring state implementation has been affirmed (*Bond v. Stanton*, 1974). While Medicaid is a payments program, Title V of the Social Security Act authorizes federal funding for state-operated health care delivery and prevention programs (maternal and child health and crippled children's services). Maternal and child health services are directed toward prevention, comprehensive health services for children and pregnant women, and child health supervision. Specific project areas authorized through 1974 included maternity and infant care projects, intensive care of infants, health care for preschool and school-age children, and dental care.

Title V also established a formula grant program for services to crippled children. Services under this program may include identification; diagnosis; medical, surgical, and corrective services; and hospitalization and aftercare of children "who are crippled or who are suffering from conditions leading to crippling." Under the Social Security Act, a crippled child is defined as "an individual under the age of 21 who has an organic disease, defect or condition which may hinder the achievement of normal growth and development."

Programs are operated through agencies that are established under state law and that have a great deal of flexibility in defining the target population and priorities of service for the small amount of monies available.

Although federal funding of health services (approximately \$35 billion in fiscal year 1975) is having an increasing impact on entitlement to medical care, almost all programs are funneled through state administrative channels, and entitlements often involve complex interpretations of federal and state law and regulations. The extensive legal and regulatory framework provides an excellent area for establishing rights to medical treat-

ment even though the service required may be considered by the state as exceptional and not within the fiscal capacity of the program (*Roberts v. Brian*, 1971). One should recognize that each state has some form of statutory authority that mandates the state or local government unit to provide health care services to the indigent either through a system of public hospitals or purchase arrangement. One may argue that federal-state medical care schemes do not define exclusively the state responsibility to provide adequate medical care. The 1974 Supreme Court in *Memorial Hospital v. Maricopa County* (94 S. Ct., 1974) gave some indication that entitlement to medical care carried at least the same level of fundamental interest as entitlement to welfare. Pending the enactment of comprehensive national health insurance with adequate coverage for disabled persons, litigation, especially comprehensive right to treatment suits, will continue to test the limits of state responsibility to provide adequate medical care to disabled citizens.

Mobility and Transportation

It is hornbook law that "the man who is blind or deaf or lame or otherwise physically disabled is entitled to live in the world" (Prosser, 1964). Jacobus tenBroek (1966) has eloquently elaborated this legal principle as follows:

The right to live in the world entails at least a right to free and safe physical access to it through the use of streets, sidewalks, roads, highways, and the common modes of transportation, communication, and interchange. It includes as well full and equal access to places of public accommodation, places designed to accommodate men in the course of gaining access to the world.

The right of handicapped people to move freely in the community and to have equal access to public buildings and transportation is explicitly recognized in many state civil rights statutes and is implicit in the myriad of architectural-barriers laws and white cane laws. However, despite these laws, exclusion of handicapped persons from public facilities seems to be an increasing problem, and enforcement likely depends on action through the courts. Before an examination is made of current legal action, consideration should be given to the extensive body of law supporting integration of handicapped persons into the mainstream of community life.

White cane laws protect blind and visually handicapped persons in each state. These laws all have certain common features concerning coverage for blind and partially blind, use of guide dogs,

color and position of cane, duty of motor vehicle drivers toward blind persons, immunity of blind persons, and penal sanctions (Mass. Gen. Laws, Chapter 90, Section 14(a)). Some statutes also guarantee access to public accommodations (ten-Broek, 1966).

White cane laws have been supplemented in about half the states by comprehensive civil rights acts that protect blind and other disabled people against discrimination in public accommodations, housing, and other areas (Fla., Stat. Ann. Section 413.08). While some of these newer statutes still employ criminal penalties, the better approach to enforcement is found in those states that extend the jurisdiction of the civil rights commission to take action in cases of discrimination against the handicapped.

Architectural-barriers legislation, which prohibits to varying degrees the construction of public buildings that are inaccessible to physically handicapped persons, also exists in some form in almost every state (President's Committee on Employment of the Handicapped, 1971). While provisions vary from state to state, the statutes originally enacted in the 1960s have been criticized as ineffective. Coverage is generally limited to new public buildings, enforcement is diffuse and weak, and the statutes are riddled with waiver clauses. Dissatisfied with state legislation which has failed to protect them, handicapped persons have lobbied for reform legislation and are now turning to the courts to raise claims under the U.S. Constitution and federal law to achieve equal access to buildings and transportation. An initial and significant step in this direction was taken in the lawsuit of *Friedman v. County of Cuyahoga* (Case No. 895961, 1972).

Friedman, an attorney confined to a wheelchair, attempted to enter five county buildings in Cleveland, Ohio, four of them housing courtrooms. He could not enter any of them without assistance. He filed a class action suit in the Court of Common Pleas for the County of Cuyahoga, seeking a declaratory judgment as to right to access and injunctive relief. Since the buildings are not covered by the Ohio architectural-barriers statute, the legal action was based on rights guaranteed by the U.S. and Ohio constitutions.

The plaintiff argued that the acts of the county commissioners in maintaining barrier-laden buildings amounted to: denial of access to the courts; denial of access to a seat of government in derogation of the right to free petition; denial of right to travel and freedom of movement; and

denial of equal protection in that the barriers unjustifiably limited equal employment opportunity. These infringements on constitutional rights, Friedman asserted, placed a burden of affirmative action on the county commissioners to provide access to all handicapped citizens.

The lawsuit was resolved by agreement of the county commissioners to install ramps and to ensure accessibility to all existing county-owned buildings. The judicially approved consent decree also provided that all county buildings constructed in the future must conform to accessibility standards.

The federal Architectural Barriers Act, first enacted in 1968 (PL 90-480, 42 USC, 4151) has also been the vehicle for successful litigation. Legal action to secure access to public transportation arose when officials responsible for planning, design, and construction of the Metro subway system for the nation's capital failed to comply with the federal law.

In 1970, Congress enacted PL 91-205, which added clarifying amendments to the Architectural Barriers Act of 1968. The amendments mandated that subway stations, surface stations, and other structures of Metro be accessible to the handicapped. The original plans for an Adopted Regional System agreed to under the terms of a compact among the District of Columbia, Maryland, and Virginia made no provision for accessible facilities (capital costs covered escalators rather than elevators). After passage of PL 91-205 no changes were made, contracts were let, and construction continued without provision for elevators.

Suit was filed in U.S. District Court, petitioning for a declaration that Metro was in violation of federal law and an injunction preventing Metro from making further expenditure of construction funds or taking any other action that would make the installation of elevators more difficult or costly (*Urban League v. WMATA*, 1972). A preliminary injunction was denied, based partially on the public interest in maintaining the construction schedule and upon the belief that Metro officials would take steps to redesign stations and to install elevators. However, Metro officials consistently maintained that the 1970 amendment to the Architectural Barriers Act was simply an authorizing statute and an appropriation of \$65 million earmarked for the handicapped was required before action on installation of elevators could be effected.

For over three years, Metro officials held to the view that any expenditure of funds for the handicapped (even funds raised from sale of revenue bonds authorized subsequent to the congressional mandate that Metro be accessible) would be a diversion of funds from the Adopted Regional System. This position changed only upon the issuance of an injunction by Judge William Jones, preventing Metro from opening any stations for use unless and until stations were equipped with inclined elevators.

Since the suit, Congress has strengthened the enforcement potential of the Architectural Barriers Act, authorizing the creation of an Architectural and Transportation Barriers Compliance Board (PL 93-112, Section 502). The board has a wide ranging power to conduct investigations, hold public hearings, and issue orders to ensure compliance with the Architectural Barriers Act (Architectural and Transportation Barriers Compliance Board, 1974).

Advocates of the handicapped are also bringing federal suits under Section 504 of the Rehabilitation Act and the Urban Mass Transportation Act (UMTA) of 1964. The UMTA, as recently amended, declares, as the national policy, that "elderly and handicapped persons have the same right as other persons to utilize mass transportation facilities and services" and further requires that "Federal programs offering assistance in the field of mass transportation should contain provisions implementing this policy" (49 USC, Section 1604).

While the Department of Transportation has made demonstration grants under this authority and has proposed some regulations that set forth certain accessibility requirements (UMTA, 1975), suits have been filed that claim that the Urban Mass Transportation Act requires more and that this act, the equal rights provision of the Rehabilitation Act (Section 504), and portions of the Architectural Barriers Act are violated by public officials who use federal funds to develop, construct, or maintain new transit facilities without making adequate provisions for accessibility for the handicapped and elderly. In at least one federal court suit, *Disabled in Action v. Hughes*, the defendant state, municipal, and federal officials agreed to provide accessible buses for the handicapped in Baltimore (C.A. No. 74-1069, 1974). In a suit filed in Hawaii, plaintiffs have requested the federal district court to enjoin the purchase of any new buses for Honolulu unless adequate steps are taken to ensure that the handicapped have equal access to the entire transportation system (*Abilities Unlimited, Inc. v. Villegas*, 1975).

Constitutional and statutory claims are also being raised to challenge denial of access to air transportation. Handicapped persons, especially wheelchair-bound persons, are regularly denied passage on commercial air carriers, and these incidents have received considerable attention in the past two years. Although the Federal Aviation Administration and the Civil Aeronautics Board, two agencies that have regulatory authority over commercial air carriers, have proposed regulations that prohibit discrimination against deaf persons and blind persons (but not deaf-blind persons), the proposed regulations (1) condone, in the interest of flight safety, the exclusion of certain handicapped persons unless accompanied by an attendant; and (2) limit the number of handicapped persons on any single flight (Department of Transportation, 1974). The overall effect of existing procedure and proposed regulations is to subject mobility-disabled persons to the whim of airline personnel. Especially hard hit are those persons who must use air travel in the course of employment. More important than the number of persons affected by the present practices of air carriers and the nonfeasance of the regulatory agencies is the fact that a fundamental right, such as the right to travel, has been denied to a class of persons on the bases of conjecture and hypothesis and without any rational basis whatsoever. It will take court actions raising constitutional right to travel, as well as rights under the civil rights section of the Rehabilitation Act (Section 504), to secure equal access to air transit. The federal suit of *Thoben v. Eastern Airlines* (C.A. 74-937, 1974), in which a wheelchair-bound civil service employee traveling on business was twice denied passage from Washington, D.C. to Philadelphia, will most likely be the first case in which a ruling is made on the constitutional and statutory claims as well as the liability of airlines for damages for unlawful exclusion of handicapped persons. The precedent that will be established may have an impact not only on air travel but also on access to all forms of transportation and will thereby have considerable bearing on the disabled person's right to live in the world of the 1970s.

Summary and Conclusion

A large body of federal and state legislation that applies to deaf-blind persons is now in existence. Also, a number of legal action strategies have been developed on behalf of other handicapped persons, and these can be used by deaf-blind persons and their advocates. This description of the state of the law merely provides a starting point to evaluate the

legal structure as it applies to deaf-blind persons. Such an evaluation can be approached by building upon a typology of services and legal claims to services developed by Gilhool (1975). He classified services as follows:

1. Services that are available to all citizens (e.g., fire protection, police protection, and education)
2. Services that are available to all citizens and that handicapped persons would use in a special way (e.g., access to public buildings)
3. Services that are available to some citizens on the basis of conditions that are not related to handicap (e.g., public assistance or medical assistance based on need)
4. Services that are available to handicapped citizens specifically (e.g., model centers for the deaf-blind)

Gilhool further cites two types of claims with respect to the four types of services: (1) a claim for access to the service; and (2) a claim for quality of service. He cautions against drawing direct claims of affirmative constitutional rights to services and argues persuasively that education, employment, recreation, and other services can be cast as Type 1 services and that such services can be advanced through equal protection bolstered by principles of normalization. Using this model, the deaf-blind may be able to access a number of services that are not specifically intended for them by pressing claims to Type 4 services for the blind and services for the deaf. All statutory definitions governing programs outlined herein are broad enough to include deaf-blind persons, and exclusion of such persons on the basis of multiple handicap could be attacked without reaching constitutional questions.

Even if access to education, treatment, employment, and other services could be gained by deaf-blind persons, the question of quality of service remains. As noted in the sections on education and treatment, courts can and will address issues of quality in instances in which due process is involved. In the case of many deaf-blind persons, questions of provision of service inevitably raise questions of control, and these must be dealt with in terms of due process and the personal liberty of the deaf-blind person.

With the wide variety of legal claims and strategies to be employed on behalf of deaf-blind persons and the myriad of legal provisions that come into play, the major gap in the law becomes evident. The deficiency relates to the practical problem of negotiating a complex system of generic services and entitlements by, or on behalf

of, a person who may be highly dependent and who may receive low priority within the range of clients being served. While procedural due process mechanisms such as hearings in education, an individual's plans for rehabilitation, and periodic review procedures in residential settings are now available, they may be of little use to the deaf-blind client unless special provisions are activated to ensure that his or her rights are protected. The protection, representation, and advocacy required may be provided in a number of ways: through a specialized advocacy agency; through a case manager, as suggested by Hammer; or through a personal surrogate (Hammer, 1974). Whatever the form, new legal provisions to define the legal relationships between deaf-blind persons, parents, and guardians and advocate-surrogate, service providers, and the community at large must be developed. These provisions should recognize the responsibility of those in a legal relationship to the deaf-blind persons to protect and assist them while allowing for their growth and development and preserving their right to as much independence as possible.

The development of such a legal arrangement together with the continuing expansion of the rights of the handicapped through future legal action will do much to guarantee that all handicapped persons, including the deaf-blind, receive equal treatment under the law and have the full opportunity to develop their potential and contribute to the general welfare as they are able.

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Touch Communication¹

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How can others communicate with us through the sense of touch? Our success in finding answers to this question will determine significantly our freedom and our happiness as persons who are deaf and blind.

Little children can show us one way. Toddlers take our index finger and point to the thing or place in which they are interested. They bring their favorite toys and place them in our hands. They lead us to the kitchen sink to show that they want a drink of water. They pat our hand or climb into our laps and give us a hug to show affection. They express themselves by gestures and by actions.

Universal Communication Methods

Taking his deaf-blind father's hand, a three-year-old boy signals "yes" by moving the hand up and down, "no" by moving it back and forth. To show pride in some new accomplishment, he seizes his father's wrists and claps his father's hands together as if applauding. If hurt in a fall, he brushes his father's fingertips across a tear-wet cheek. If he wants something, he finds ways of letting the fact be known!

Adults, too, can use the language of gesture and action, as "the kiss that speaks volumes" happily illustrates. If our friends do not instinctively realize how thoughtful or time-saving a gesture or action can sometimes be, a tactful suggestion on our part will usually be welcomed. By a slight, continuing pressure on our hand, for instance, a friend can let us know he is speaking to someone else in the group. The pressure not only saves us from interrupting, but also conveys a sense of companionship and assurance that we have not been forgotten.

We can always secure information or even carry on a kind of conversation by asking questions that can be answered by a "yes" or "no." Many deaf-blind people interpret one tap as meaning "yes," two taps as "no," three taps as "I don't know." Be sure, however that you and the other person are in agreement on the meaning of the signals, for there is as yet no universally accepted standard. A sample interchange by this method might be:

"Nice of you to stop tonight, Mr. Brown, to take me to the meeting of the chess club. Is the weather good?"

"No."

"Is it raining?"

"No."

"Good heavens, are we having our first snow of the winter?"

"Yes."

"Do I need to wear galoshes?"

"Yes."

"Thanks for warning me. The last thing I want to do is get wet feet and catch cold."

Success with this method depends on asking questions in a logical order, beginning with general questions and proceeding to particular ones. Be sure to avoid double inquiries, such as "Is the room too warm or too cool for your comfort?" To answer such a question with a yes or no would tax the wisdom of Solomon! The tactful questioner will also avoid such queries as the famous "Have you stopped beating your wife? Answer yes or no."

Yet for a full-fledged, satisfying conversation, we do need communication through words. Unless one has received long, arduous, and difficult training in reading lips by touch—training available

¹ Excerpted from *Independent Living Without Sight and Hearing*

at only a very few schools that specialize in the teaching of deaf-blind children—the words must be spelled out letter by letter. Many and varied methods have been worked out by which this can be done with surprising speed. Some of the most rapid and convenient methods require special learning on the part of both the deaf-blind person and the person speaking to him. We will consider these a little later. Now, however, let us discuss some “universal” communication methods that almost anyone can use to converse with us immediately—provided we ourselves are ready.

The deaf-blind person who learned to read print before losing his or her sight will find the knowledge invaluable. He or she can carry a pocket-sized alphabet plate that bears raised print letters easily recognized by touch. A friend, an acquaintance, even a stranger, can communicate at once simply by taking the deaf-blind person's index finger and placing the tip on the desired letters as words are spelled out. The alphabet plate has extra advantages for the deaf-blind person who cannot use his or her voice, since he or she can in turn point to the raised letters in spelling out his or her own side of the conversation. If we have not read print for a long time or if we have never read it and must learn from the beginning, the alphabet plate offers excellent practice. The raised letters are always there to be studied or reviewed, and the method can be used as slowly as is necessary.

Once our skill in recognizing print letters is adequate, a much faster method than use of the embossed alphabet plate becomes possible. The person to whom we are talking can simply print capital letters—often called block letters—in the palm of our hand with the tip of his or her index finger. Block letters may be received in either hand, depending on which is more comfortable. Raise the hand forward, waist-high with elbow bent, elbow touching the side, palm up, fingers extended together. Ask the other person to print capital letters on your palm, making the letters large and one after the other on the same spot. When both hands are occupied with work, some deaf-blind people receive block letters printed on the shoulder or back. At least in the beginning, you may find print letters easier to recognize if the other person holds your own index finger like a pencil and prints on a table or in your other hand.

As with any other communication method, printing in the palm takes practice to master. Printing in your own palm several times a day will help you build skill. The method has the great advantage that nearly every sighted person knows

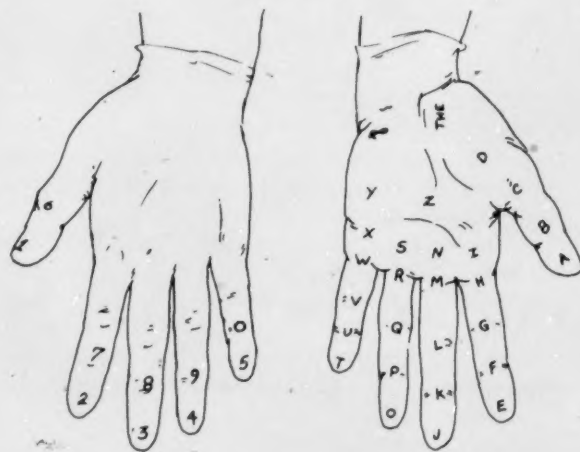
how to print—and a large number of blind persons do, too. Your hand is always with you—on the street, on the beach, at work. The method has no special equipment to forget or mislay.

Sometimes the deaf-blind person who lost his or her sight in childhood finds printing in the palm difficult to learn or to read with speed. What are the other methods by which we can take advantage of the fact that almost all sighted people are familiar with print?

Alphabet Glove

One such other method is the alphabet glove—a thin, white cotton glove on which the letters of the alphabet have been printed with indelible ink at definite spots memorized by the deaf-blind wearer. The sighted person spells out his or her words by touching the letters. With practice, the method can become very quick. Because the letters are systematically arranged, their positions are easy to memorize. The glove is convenient to carry. Friends who use it often will soon find that they have unconsciously learned the locations of the letters, just as we have, and thereafter they can use the alphabet glove method without a glove!

With the help of a friend, each of us can provide his or her own glove, thereby ensuring a perfect fit. The glove is usually worn on the left hand, and the wearer extends his or her hand away from himself or herself toward the speaker. After we have purchased a suitable white cotton glove, the friend assisting us should mark it with indelible ink in such a way that the print letters appear right side up for the person facing the wearer. The letters of the alphabet are printed on the palm side of the



Back of left hand

Palm of left hand

glove and are located on the tips of the fingers, the joints of the fingers and the palm of the hand at the base of the fingers while the numerals appear on the fingernails and knuckles on the back of the hand.

The arrangement of the letters and numerals on the glove is systematic and is as follows:

The Letters

Extend the left hand with the palm face up. The first four letters are located in the line of the thumb:

- A—tip of the thumb
- B—first joint of the thumb
- C—second joint of the thumb
- D—palm of the hand at the base of the thumb
(the section commonly thought of as the fleshy part of the thumb)

The next five letters are located in the line of the index finger:

- E—tip of the index finger
- F—first joint of the index finger
- G—second joint of the index finger
- H—third joint of the index finger
- I—palm of the hand at the base of the index finger

The next five letters are located in the line of the middle finger:

- J—tip of the middle finger
- K—first joint of the middle finger
- L—second joint of the middle finger
- M—third joint of the middle finger
- N—palm of the hand at the base of the middle finger

The next five letters are located in the line of the ring finger:

- O—tip of the ring finger
- P—first joint of the ring finger
- Q—second joint of the ring finger
- R—third joint of the ring finger
- S—palm of the hand at the base of the ring finger

The next six letters are located in the line of the little finger:

- T—tip of the little finger
- U—first joint of the little finger
- V—second joint of the little finger
- W—third joint of the little finger
- X—palm of the hand at the base of the little finger

- Y—palm of the hand midway between the third joint of the little finger and the wrist
- Z—center of the palm

The Numerals

Extend the left hand so that the palm is facing down. The first five numbers are located on the fingernails:

- 1—thumbnail
- 2—nail of the index finger
- 3—nail of the middle finger
- 4—nail of the ring finger
- 5—nail of the little finger

The next five numbers are located on the knuckles:

- 6—the first knuckle of the thumb
- 7—first knuckle of the index finger
- 8—first knuckle of the middle finger
- 9—first knuckle of the ring finger
- 10—first knuckle of the little finger

As with printing in the palm, a good way to build up speed in using the alphabet glove is to practice talking to ourselves, tapping out the words on our own hand. Be sure to memorize the location of the letters thoroughly before trying the glove with others. Blind friends can of course talk to us by this method only if they themselves also learn the position of the letters. You may be pleasantly surprised by the number of people with whom you can become "hand in glove!"

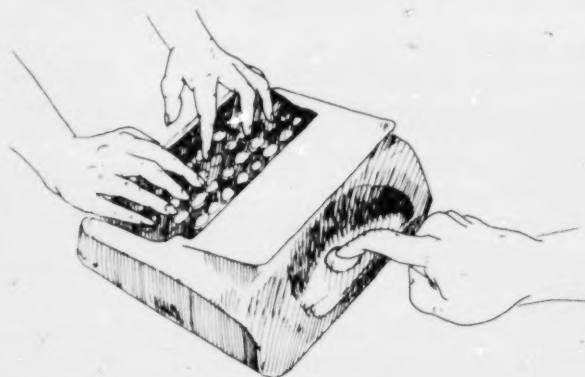
Braille Alphabet Card

A slow but simple method enables the deaf-blind person who can read braille to capitalize on the universal familiarity with inkprint of the sighted public. This method is the use of the braille alphabet card, a pocket-size card that bears both the inkprint and braille alphabet. A sighted friend can use the card by placing our index finger tip on the braille letter just below the equivalent print letter. A blind friend can use it by locating the braille letter he or she wishes to indicate and placing our finger tip upon it.

Tellatouch

Finally, an outstanding communication device for the good braille reader is the Tellatouch, a small machine resembling a miniature typewriter that raises corresponding braille letters under the deaf-blind reader's finger tip as the other person types. With practice, the Tellatouch can often be read at 60 words a minute or more, and the schools teach typing to so many people nowadays that a

good share of the persons we meet may actually be touch typists. Even those who cannot touch type are usually at least somewhat familiar with a typewriter keyboard and can do reasonably well by the famous one-fingered "search and sock" method. Further, the Tellatouch seems to appeal to a kind of toy instinct in many people, its use striking them as an enjoyable sort of game. Children love it especially—as do all who are young in heart and gadget conscious. To put a new friend at ease in using the Tellatouch, we can helpfully suggest that the capital sign be omitted for simplicity's sake. We should explain that the braille is easier to read if the typist presses the key all the way down rather than striking with a sharp, staccato motion. A blind friend should be warned that the keyboard omits the usual top row of numbers. Numbers are best spelled out. Someone who knows braille may prefer to use the six Braillewriter keys at the bottom of the keyboard rather than the typewriter keyboard itself.



Tellatouch

To develop our own ability to read the Tellatouch fluently, we can practice with advantage the often-repeated suggestion of talking to ourselves. By pressing the keys at random with one hand and identifying the rising braille characters with the tip of our favorite reading finger on the other hand, we can greatly enhance our reading skill with the device.

The Tellatouch is light and portable. It can be carried about as easily as a lady carries her handbag. Tellatouches are available from the American Foundation for the Blind in New York at a price well worth the investment.

Let us return for a moment to the subject of communication by gesture or action. A man's name is to him the sweetest sound in the language and the friend who has a special "name sign," such

as linking the little fingers, squeezing the shoulder, rippling the finger tips across the back of the hand, will enjoy saying hello to us at every opportunity. By giving our friends clever name signs we can promote the beginning of many fine conversations!

Special Communication Methods

We have discussed some communication methods that we termed universal because almost anyone can use them at once in communicating with us, provided that we ourselves are skilled in their use. Now let us discuss some communication methods that are special because their use does not require some special learning on the other person's part, no matter how well prepared we who are deaf-blind may be.

The question naturally arises regarding whether we should concern ourselves about special methods at all. Why not stick to universal ways that others can use at once? Will not other people always speak to us more often, more readily, and with more pleasure if they do not need to learn or remember special codes? The questions have a point, and some deaf-blind people do indeed rely on universal communication methods, certain of which, like the alphabet glove or the Tellatouch, are capable of impressive speed. Every deaf-blind person should definitely know at least one universal method by which others can communicate with him or her immediately. Such knowledge may be vital in an emergency. Even in a social sense, we will never be able to mingle freely in a group or acquire new acquaintances readily unless we have at our disposal a communication method that others will find rewarding from the start. If we can offer others a choice of such methods, so much the better. People tend to do again what they enjoy doing, and they will enjoy talking with us much more if they are offered a variety of methods from which to choose their favorite.

And this is exactly the point to which we have been leading. Though agreeing that knowledge of universal methods is necessary, many deaf-blind people also have one or more special methods they find congenial when talking among themselves, with members of their families, or with friends whom they meet often. The special method may be a favorite because of its speed, the warm personal hand contacts it involves, the particular uses to which it can be put, or simply because it seems relaxed and comfortable. Also, experience indicates that once a new acquaintance becomes sufficiently interested to learn a special method, he

or she is likely to grow so proud of his or her new skill that he or she takes every opportunity to use it!

In the United States, the one-hand manual alphabet is the most widely used special method. One of its merits is the possibility of flashing speed, a factor that has made it a favorite among deaf-blind college students. Another advantage is that it can be used in almost any position without need to look at the hands or to feel for specific areas on them. This manual alphabet reflects the personality, mood, and emphasis of the speaker to a remarkable degree, and the enthusiast who once described it as "an aristocrat among peons" may in some ways have been justified.

On the other hand, no pun intended, the one-hand manual alphabet is complicated to learn. It requires considerable practice to use with speed and even more practice to read with facility. Anyone with stiff joints or arthritic fingers will experience difficulties. Further, the one-hand manual alphabet is subject to many small variations from person to person. Two people, both of whom feel they know the system well, often find it necessary to go through the alphabet together for a brief comparison of letters before they can converse readily. Though the manual as used by deaf-blind persons in the United States is based on the system as employed by the sighted deaf, the latter form their letters in the air for visual reading and preliminary explanation of how to form them in the hand is often helpful.

The One-Hand Manual Alphabet

The listener places his or her hand lightly over (some prefer under) the speaker's hand to feel the position of the speaker's fingers. The speaker should be careful to move the fingers directly from the position of one letter to the next and to pause briefly between words. The listener should keep his touch as light as possible and avoid "strangling" the speaker's fingers in the manner of an affectionate octopus.

The position of the hand, unless otherwise specified, is up with the palm turned away from the speaker. The elbow should point down, the shoulder should be relaxed, and most of the action should be from the wrist through the fingers.

A—Fold the four fingers flat against the palm and point the thumb up, holding it tightly against the bent index finger.

B—Point the four fingers straight up, holding them tightly together, and bend the thumb across the palm.

C—Holding the four fingers together, curve them downward and curve the thumb upward toward the tip of the bent index finger (looks like a print C).

D—Point the index finger straight up and make a circle with the tip of the middle finger and the thumb. The fingers are curved tightly together.

E—Bend the thumb across the palm and place the tips of the four fingers tightly together along the upper edge of the thumb.

Stop at this point and review. Actually make the letters with your right hand. Spell in the air when practicing alone. Practice the words in the following list, all of which can be spelled from letters you've already learned: bed, bad, dad, ace, decade, ebb, beaded, cede, cad, bade.

F—Bend the index finger forward. The other three fingers and the thumb point straight up. Hold the fingers tightly together and place the thumb against the second joint of the index finger.

G—Drop the hand by bending the wrist so that the hand is horizontal and the palm inward. Point the index finger and the thumb, curling the other three fingers into the palm (the thumb and index finger nearly touching). (G may stand for the gun that you appear to be pointing).

H—This letter is made exactly like G except that the middle finger also is pointing, held tightly against the index finger.

I—Make a fist and point the little finger straight up.

J—Starting with I, bring the tip of the little finger down and then up to the left in a hook, moving the whole hand from the wrist. (You are drawing the letter J.)

Time to review again. Spell the following words in the air, checking for accuracy whenever in doubt: fig, feed, head, high, jab, ice, each, chef, beached. We are chewing the one-hand manual alphabet a mouthful at a time to prevent indigestion.

K—Point the index and middle fingers straight up, separated. Place the tip of the thumb between the two fingers at the base. The ring and little fingers are curved into the palm.

L—Point the index finger straight up and thumb at right angles to it. The other fingers are curved into the palm.

American One-Hand Manual Alphabet



A



B



C



D



E



F



G



H



I



J



K



L



M



N



O



P



Q



R



S



T



U



V



W



X



Y



Z

M—Holding the little finger down with the tip of the thumb, bend the index, middle and ring fingers over the thumb, holding them tightly together and pointing downward.

N—N is made exactly like M except that the ring and little fingers are held down with the tip of the thumb and only the index and middle fingers are bent over the thumb.

O—Make a circle with the four fingers and the thumb by placing the tip of the thumb against the tip of the index finger, holding the four fingers tightly together.

After reviewing the last five letters and any earlier letters about which you may feel qualms, spell in the air the following words: look, moon, balloon, knee, moan, and, foam, diamond, beneficial, bleak, and macaroni. The alphabet has been divided at various times into groups of similar letters, with somewhat mixed results. Some learners thought the grouping of similar letters helped them memorize. Others felt the system merely gave them one more thing to keep track of—that is, which letters are in which groups. In this paper we are presenting the letters in squads of five, each squad followed by appropriate practice words, and the result should be straightforward, morale-boosting progress from A through Z.

P—By bending the wrist slightly, drop the hand halfway, extended away from self with the palm turned down. Point the index finger out and the middle finger down. Place the ball of the thumb against the first joint of the middle finger and curl the ring and little fingers into the palm.

Q—Q is made exactly like G except that the whole hand is pointing downward and the thumb and index finger are slightly more separated.

R—Make a fist with the index and middle fingers pointing up—middle finger crossed over index finger.

S—Make a fist with the thumb across the front of the fingers to touch the second joint of the ring finger.

T—Make a fist with the tip of the thumb pointing up between the index and middle fingers.

U—Make a fist with the index and middle fingers pointing up straight, holding them tightly together.

We have added a bonus sixth letter to the usual group of five this time—and for excellent reason. How often could we use Q in spelling a word if we

do not also know how to sign U? After reviewing the letters in this fourth group, spell in the air the slightly bizarre thought: Peter Piper quaffed a quart of simple mountain seal oil.

V—Make a U with the index and middle fingers separated (looks like a letter V).

W—Point the index, middle, and ring fingers up, holding them separated, and curl the thumb and little finger into the palm (looks like a letter W).

X—Make a fist and raise the index finger by straightening it at the knuckle joint but keeping it bent at the other two joints to look like a hook.

Y—Point the little finger and thumb up straight with a slight outward slant. The other three fingers are bent down.

Z—Make a fist and point the index finger. With the tip of the index finger, draw a zigzag as follows: make a horizontal stroke from left to right, a diagonal stroke down to the left, and a horizontal from left to right. Imagine your index finger printing the letter Z.

Which letters of the one-hand manual alphabet resemble print? After reviewing the last five letters, spell in the air: a fox, a walrus, and a young zebra—just the kind of company I've always wanted on an exciting night in Paris.

There are almost as many ways of reading or listening to the one-hand manual as there are people to read or listen. Some prefer to have the letters made straight down into the palm. Some like to touch the back of the speaker's hand with both of their own hands. The right method is the one that proves to you to be the clearest, most comfortable, most rapid, and least likely to cause misunderstanding or to require repeats.

The one-hand manual alphabet is a challenge to each of its users. Like a spirited horse, it needs to be mastered through individual patience and skill.

The Two-Hand Manual Alphabet

In Great Britain and in most other English-speaking countries except the United States, the two-hand manual alphabet is the most popular special communication method. The descriptions "one-hand" and "two-hand" refer to the ways in which the letters are made. With the former, the speaker forms a complete letter with his or her hand and the hand of the listener is expected to recognize it. With the latter, both the speaker's hand and the listener's hand are essential to form a letter, though the listener's hand remains open and

perfectly quiet. The distinction is at best somewhat technical and need not detain us here. Many users of the one-hand manual, for instance, actually blend the two ways of reading.

The two-hand manual alphabet has certain very real advantages to offer. It is simpler, easier to learn, perhaps easier to read. The fact that many of the letters resemble print letters is a memory aid to friends with normal sight. The greater simplicity of the letters means fewer variations from person to person in the way the letters are formed. Though the two-hand manual alphabet does not usually lend itself to such dazzling speech as a few have attained with the one-hand manual alphabet, it does offer a reasonable pace for most and is especially kind to anyone with stiff fingers. As one often-dated, deaf-blind coed who knows both manuals demurely put it: "I choose my manual to suit my man."

Ideally, the speaker should sit beside the listener, to the listener's left. He or she should take the listener's left hand, resting the back of it on his or her own left palm. The speaker then makes the letters with his or her own right hand on the listener's left hand in the following ways:

The five vowels, A E I O U, are indicated by tapping the listener's fingertips in this order: thumb, index finger, middle finger, ring finger, and little finger.

B—The fingers are bunched so that the tips meet in an irregular ring and placed in that form in the palm of the hand.

C—The index finger makes a circular flick along the inner side of the thumb and along the curve between the thumb and the index finger, finishing at the tip of the index finger.

D—The tip of the index finger touches the tip of the listener's index finger, while the tip of the thumb touches the base of the index finger.

F—The index and middle fingers are placed close together at right angles across the index finger.

G—The fist is clenched and placed in the palm, with thumb in highest position and little finger on the palm.

H—The palm of the speaker's hand is moved swiftly across the listener's palm. (The motion suggests the breathy sound of H.)

J—The tip of the index finger touches the tip of the middle finger and strokes down it to the base.

K—The index finger is bent, palm turned down, and the bent second joint touches the second joint of the listener's index finger.

L—The index finger is laid across the palm.

M—The first three fingers, touching, are laid across the palm.

N—The first two fingers, touching, are laid across the palm.

P—The tip of the index finger is lightly held by the tip of the index finger and thumb. (This letter is simply a pinch of the tip of the index finger.)

Q—The index finger is placed in the fork between the index finger and the thumb and hooked round the base of the thumb.

R—The index finger is bent and laid across the palm.

S—The index finger is bent and linked with the little finger.

T—The tip of the index finger should touch the edge of the palm at the side farthest from the thumb.

V—The index and middle fingers are separated as far as possible and laid across the palm.

W—The palm of the hand is laid flat across the fingers and the fingers are bent over and round the fingers.

X—The index finger is laid at right angles across the index finger.

Y—The index finger is placed in the joint between the thumb and the index finger.

Z—The tips of the fingers in a row touch the middle of the palm

The speaker should pause briefly between words. If both speaker and listener are familiar with contracted braille, abbreviations may be used. However, when a really good rate of speech has been worked up in either the one-hand or two-hand manual alphabet methods, most people find that abbreviations cause more confusion than they are worth. One exception is to abbreviate a long name by using just its first syllable, such as abbreviating Mr. Nuttingham into Mr. Nut. Obviously, even here there is danger if the deaf-blind person habitually shortens his spoken speech to match the abbreviation!

The International Morse Code

The International Morse Code merits discussion in this chapter because it will prove itself invaluable in connection with the telephone. Even as a straightforward communication method among persons within touching distance of one another, the International Morse Code has the advantage of being inconspicuous, applicable to any part of the body, potentially rapid, and familiar to many Boy and Girl Scouts, members of the Armed Forces,

and amateur radio operators. At its simplest, the dash is merely a stroke with the tip of the index finger, the dot a tap. When written in braille, braille dot 1 is used for the code dot and braille dots 1 and 4 are used for the dash.

A ---	N ---
B ----	O ----
C ----	P ----
D ---	Q ----
E ..	R ---
F ----	S ---
G ----	T ---
H ----	U ---
I ..	V ----
J ----	W ----
K ---	X ----
L ----	Y ----
M ---	Z ----

Our Response

Since conversation is a two-way affair, we must have something to contribute. The man or woman who is deaf, blind, and mute has an extra challenge to overcome in carrying on successful communication—and many such people have shown heartwarming resourcefulness in doing so.

In the first place, one can often convey one's thoughts in writing. A pencil and pad are handy if

one knows penmanship. Messages can be typed on file cards and labeled in braille for use in later situations, as when traveling. In fact, many deaf-blind people with clear speaking voices find file cards bearing typed addresses or instructions a good thing to carry when they wish to make doubly sure they are understood. Several very small portable typewriters are now produced that will even fit into a suitcase. For braille-reading friends, the Perkins or Lavender Brailers, the miniature Banks Pocket Writer that brailles on a thin ribbon of paper, and the ordinary pocket braille slate and stylus offer resources.

Printing in the air, manualing in the air, and pointing to the letters on a braille or raised-print alphabet board are practical methods. Others must necessarily spell out their words to us. Those of us who cannot speak must simply spell right back to them in the clearest and most mutually congenial way.

Each person's voice is distinct, a product of his or her physique, personality, background, and special problems. Regarding our individual strengths and weaknesses, we can ask for candid opinions from our friends. We may also profit from discussing specific speech problems with professional speech therapists or with deaf-blind persons who have done notable work in building their own voices.

The author of this will now stop and read what he has written—aloud. Nothing does more for a voice than daily reading aloud.

The Current Status of Information and Service Resources for Deaf-Blind Persons in the United States in 1975

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The sudden appearance of significant numbers of deaf-blind babies in the United States ten years ago highlighted in a dramatic way the absence of a coordinated, instantly responsive information system for use by parents and professionals to match children's needs with appropriate services. Professionals were hampered in responding to the rubella-damaged babies by not being able to locate them, learn of the severity of their handicaps, or assess the babies' needs or those of their parents. They were unable to determine how the needs should be met or by whom, what funds were needed for the task, and from what sources the funds could be provided. The answers were slow in coming, but gradually the fact was apparent that no single agency had the answers or the responsibility for resolving the plight of the families. The conglomerate of public and private agencies offering possible information and services had apparently grown through the preceding years into a gigantic bureaucracy lacking coordination or direction.

Parents of deaf-blind babies and professionals alike became lost in the tangle of inaccurate or insufficient information and were frustrated by a profusion of referrals and agencies. They were powerless to bring the parts together effectively to help the children. Compounding the enormous human tragedy of the rubella-damaged children was the gradual realization that in America in 1965 no one-stop resource for information, no coordinating agency to ensure the provision of services, and no long-range planning for already known future information and service requirements existed. That huge information and service overlaps and gaps existed was painfully evident. Instead of an information and service delivery system, segmented bits of information and service were scattered throughout an unknown number of public and private

agencies and organizations, each of which had developed piecemeal and independently as services and "add-ons" intended at the time to be responsive to expressed human needs. Without coordination of these units, we could have no one-stop information resource, no central point for planning nor the delivery of services.

Against this backdrop, then, we report where we are in America today in information and service resources for deaf-blind persons and those interested in them. Clearly, some lessons have been learned so that from the tragedy may be the development and implementation of a workable, responsive, centralized information and service delivery system that will ensure viable, long-range planning for all eventualities. For the moment, however, we report a delivery that is improved since the dark days of the 1960s but still short of the goal. And because many direct services to parents, deaf-blind persons, professionals, and others remain scattered over and through a rather awesome number of federal, regional, state, and local public and private agencies and organizations, the sources of information have also remained scattered.

Purposes and Organization

The foremost purpose of this paper is to bring together the major sources of information and to report on the services which have the potential for being useful to deaf-blind persons. A single guide to these often elusive resources is needed and will be useful to deaf-blind persons, their relatives and friends, professional personnel, researchers, and information specialists. A second purpose is to report to the same group on the types of services needed by deaf-blind persons as stated from the perspective of program administrators, parents, and

others interested in the deaf-blind. The inclusion of this relatively new research will permit the reader to make a personal appraisal of the adequacy of the reported services to determine whether they match the expressed needs. The third purpose is to suggest possible resolutions of unmet needs.

The paper is organized in five sections, as follows: the first section presents a discussion of the reported information and service needs of deaf-blind persons, their families, and others interested in the deaf-blind. The second section, in two parts, provides public information and resources presently available and the services to deaf-blind persons. The third section of the paper offers some observations on existing and unmet needs, based on a comparison of the evidence reported in sections one and two. Section four provides a summary and listing of the various information resources such as library, directory, agency, and consultant resources, with addresses included where these may be helpful. The conclusion, section five, contains a listing of references which were helpful to the author in preparing this chapter.

Reported Information and Service Needs of Deaf-Blind Persons

Basically, information may be provided to deaf-blind persons in two ways: (1) an agency may seek out the person needing its services, a technique sometimes referred to as *outreach*; or (2) a deaf-blind person or other interested person can search for information on available services felt to be needed. The purpose of each is to improve the condition of this low-incidence, high-risk population. Agencies, groups, and institutions provide services, including financial support. Generally speaking, the services are offered through two parallel sectors, one public and one private, with the latter often receiving grants from the former. The agencies vary in important ways regarding the geographic area served, the services provided, the age of the persons served, and even the group served. They may serve deaf-blind persons directly or indirectly (e.g., training of personnel for the education or social care of deaf-blind persons). The information resource for a needed service may be as near at hand as the local area; no farther than the state capital; more distant in a multistate regional center; or most distant, as with the federal government. As a general rule, the more rural an area, the more distant the information and service resource is from the deaf-blind person needing it.

Most of the information and the services to deaf-blind persons are provided through public and private agencies serving the wider population of needy normal persons, such as the federal social security programs; through agencies providing services to the mentally handicapped, deaf, or visually handicapped persons, such as the American Foundation for the Blind; or through agencies serving the handicapped in general, such as the federal Bureau of Education for the Handicapped. Only recently two resources were established by the federal government specifically designed and oriented to meet the unusual needs of deaf-blind persons. These are the Regional Centers for Services to Deaf-Blind Children (1967) and the National Center for Deaf-Blind Youth and Adults (1969).

The most immediately useful services provided deaf-blind persons today are those offered by a complex of public agencies—federal, state, and local—through a combination of funds provided at each level. Examples of these are the health care, welfare, and education programs. Supplementing these costly, direct public services are the information resources of private agencies and organizations providing more limited but useful and specialized services.

The American public information and service bureaucracy is awesome in size and overlapping in scope. The bureaucracy is difficult to understand and use because it consists of information and services provided by hundreds of autonomous agencies, each interpreting legislation and establishing guidelines to carry out specified mandates for information and service. A maze of general laws and amendments makes provisions for needy persons, including those who are handicapped; still other laws and amendments specifically designate handicapped persons as primary concerns, including those who are deaf-blind. Missing in all of these until recently has been (1) a systematic analysis of the information and service needs of deaf-blind individuals and those serving them; (2) a thorough review of the present services and how they relate to the needs; (3) a systematic documentation of the unmet needs; (4) a plan developed for a fiscally responsible, accountable, and coordinated delivery of a total information and service program; and (5) a delivery that provides for a systematic evaluation of effectiveness of the information and services by the clients.

A recent study (Kakalik and others, 1974), completed at the request of the Assistant Secretary

for Planning and Evaluation of the Department of Health, Education, and Welfare, delineated the general needs of handicapped persons preparatory to conducting a comprehensive, cross-agency evaluation of federal and state programs for handicapped children and youth. Their list of needs for services is as follows:

1. Prevention of handicapping condition
2. Identification of those who are deaf-blind
3. Direction to appropriate service providers
4. Medical treatment to correct, alleviate, or stabilize the handicaps
5. Sensory aids and other equipment
6. Counseling of both the child and family
7. Special training, such as mobility or speech skills
8. Vocational training and job placement
9. Lifetime sheltered and semisheltered care for those requiring it
10. Recreation and social activity
11. Personal care
12. Income maintenance
13. Training of personnel to supply services
14. Construction of service facilities
15. Research

Public Programs and Information Resources

In conducting their study to determine whether the needs of handicapped youth were being met, Kakalik and Brewer (1974) described current federal and state programs for service to handicapped youth in the United States, estimated the resources devoted to various classes of handicapped youth, and identified the major problems with the present service system. The goal was to collect information that would help the federal Department of Health, Education, and Welfare improve the system as a whole, and particularly to improve the delivery of services to hearing and vision handicapped youth by suggesting alternative future policies.

The findings of the Kakalik and Brewer study suggest that the problem is not one of a lack of programs or concern or even a lack of effort on the part of service personnel. It is not a problem of indifference in parents, inferior quality of care, or even a lack of funds. Rather, Kakalik and Brewer contend the problem is the complexity of the system, the disorganization and lack of control which defy efficient and effective operation. While the findings are not specified for deaf-blind per-

sons, evidence suggests that the findings are applicable to them.

Federal Services

Generally speaking, information and services offered by the federal government may be clustered under six broad areas: (1) health programs; (2) education; (3) vocational services; (4) mental health and mental retardation programs; (5) financial assistance; and (6) research. These services are the result of the enactment of a legion of laws and the creation of an array of federal departments, bureaus, institutes, programs, and units designed to help needy Americans achieve a certain quality of life. Kakalik and Brewer identified more than 50 different major federal programs that provide information and services to handicapped youth, most of which are administered by the Department of Health, Education, and Welfare. The federal agencies provide upon request unpublished lists of agencies receiving their funds, and some of these agencies publish directories of their available services. The Office of the Federal Register, National Archives and Records Service, publishes the *United States Government Organization Manual* annually as a guide to the services of all agencies of the federal government.

State Programs

In addition to federal programs, each state operates agencies to serve handicapped persons, most of them collaborative with the federal government and needed to implement federal legislation. According to services provided they are: public health, crippled children's service, special education, vocational rehabilitation, mental health, and public welfare. Each service in each state is an information resource, providing upon request consultant assistance and information brochures describing specific services, defining eligibility, and informing eligible persons of procedures for acquiring available services.

Local Programs

Local government offers scores of services to handicapped persons, many of which services are designed to implement state and federal legislation for needy persons, including those who are handicapped. Generally, these services are: public health, education, vocational services, mental health and mental retardation, financial assistance, and often recreation and social activity. Each agency serves as an information resource offering both materials and personal contact.

Federal-State-Local Funding for Services

The program area receiving the largest portion of federal, state, and local funds for service is special education. This is followed by mental health and mental retardation and then welfare. Federal funds for the education of handicapped children, other than those who are deaf-blind, account for only about 12 percent of the total annual special education budget, with state and local agencies supporting more than 75 percent of the costs of this education. However, in the case of deaf-blind children, the federal government supports almost 100 percent of the annual cost to educate them, providing the funds through the Regional Centers for Services to Deaf-Blind Children. The reason for greater federal support of the education of deaf-blind children is the higher cost associated with their education and training as compared to other types of handicapped children. For example, during the years 1971-73, the federal government reported an annual dollar support of about \$790 per visually handicapped child, \$245 per speech handicapped child, and about \$12,000 per deaf-blind child. The higher cost of educating deaf-blind children is attributable to the severity of their multiple handicaps which require more highly skilled teachers working on a one-to-one basis with them to facilitate learning, more programs and diagnostic services, and their scattered distribution over a wide geographic area.

The number of deaf-blind persons who receive services through the second largest program, those offered through mental health and mental retardation, is not known. The two largest programs within the federal Health Services and Mental Health Administration are the Developmental Disabilities Program and the National Institute of Mental Health's Community Mental Health Center Program. Other programs in operation are St. Elizabeth's Hospital and the President's and Secretary's Committees on Mental Retardation.

The third largest expenditure of funds for the handicapped is welfare, provided through five programs: (1) Social Security Disability Insurance (SSDI); (2) Supplemental Security Income (SSI) providing aid to the blind, disabled, and aged; (3) Aid to Families with Dependent Children (AFDC); (4) General Assistance (GA); and (5) the Income Tax Exemption for the Blind (ITEB). The federal government operates all of the assistance programs, providing the services in SSDI and SSI programs and buying the services in the largest of the programs, AFDC, through state and local agencies.

Health services comprise the fourth largest public expenditure and are provided to poor and medically needy handicapped children through two programs, Medicaid and Crippled Children's Services. Several prevention programs are operated as well, the most significant to readers here being the (1) rubella immunization program; (2) the vision and hearing screening programs; and (3) other prevention programs provided to deaf-blind children through the Maternal and Child Health Care Clinics.

Vocational service agencies receive the fewest dollars of federal support but provide broad service in a federal-state collaboration administered by the federal Rehabilitation Service Administration. Assisting in this effort are the President's Committee on Employment of the Handicapped and the affiliated state and local committees; State Employment Service offices (a major federally supported program), and the National Center for Deaf-Blind Youths and Adults.

Overlap and Duplication of Services

When one considers the variety and extent of need for services to handicapped persons and the thousands of federal, state, and local public agencies that are authorized to provide services, one is not surprised at the overlap and duplication of services offered to handicapped persons. Each agency interprets its information and service mandate in accordance with the requests for services that are received. For example, one need of handicapped persons is the construction of facilities for their treatment, education and training, or care. Four types of federal, state, and local agencies provide for construction of facilities: health, special education, vocational services, and mental health and retardation. Five types of federal, state, and local agencies provide for counseling and psychiatric care. Each agency at the various levels of the federal, state, and local governments specializes in offering services in one or more needed areas and supplements its primary services with minor, less generally known services.

Health Programs

Health programs include public health, maternal and child health, crippled children's programs, Medicaid, identification, and prevention services.

The largest single health program is Medicaid, providing medical services and assistance to children, including deaf-blind children of needy families. A resource providing information on this federal-state-local program may be found at each

of the levels. At the state level it is the director of Medicaid in the Department of Public Health, and at the local level it is the public health agency. Medicaid information includes mandatory, early, and periodic screening, diagnosis, and treatment of all eligible children. How many of the more than one million children diagnosed through this program annually are deaf-blind is not known.

The second largest health program is Crippled Children's Services, providing assistance to children having almost any handicapping condition, including those who are deaf-blind. The federal Health Services and Mental Health Administration's Crippled Children's Services, the state's Crippled Children's Services office, or the local unit serve as information resources and provide medical treatment of all types through a combination of federal, state, and local funds.

Maternal and Child Health Services is the third largest health program, providing information on programs dealing with identification of handicaps in children through vision and hearing screening, dental care services, well-child clinics, public health nursing visits to mothers and children, and registration of all children found, through these and other resources, to be handicapped. All services of the Maternal and Child Health programs are administered through state and local offices with funds provided by federal and state budgets.

All of the above health and dental assistance program resources provide information on programs for the poor. The programs are quite comprehensive and approximate a system of operation. They are inequitable to the extent that identification, diagnosis, and treatment are not provided to all families, regardless of earned income. Many families able to pay for services do not search for information about services and others are unwilling to pay for them. Thus, a large number of children are not identified and do not receive early or adequate diagnosis and treatment. And since the greatest incidence of deafness and blindness occurs in the older population, we do not know how many deaf-blind adults could benefit from treatment and rehabilitation.

An information resource in the health area that is of interest to us here is one that deals with the prevention of disease and with immunization. The resource is a communicable disease prevention and control program that provides for the rubella immunization program and operates the epidemiology program of the National Center for Disease Control located at Atlanta, Georgia. The latter acts as an important national surveillance service for

diseases such as rubella and, in addition, provides consultation, technical assistance, and training for personnel in state health departments.

The Veterans Administration offers programs wherein spouses; widows; and damaged, handicapped; or congenitally malformed children of service-connected disabled veterans are eligible for diagnostic and rehabilitative services, including job-oriented restorative training beginning at age fourteen, and provides hospital, domiciliary, nursing home care, and out-patient medical services to veterans of the armed forces. The Veterans Administration regional offices serve as an information resource and currently provide services to over 200,000 children. How many of these children are deaf-blind is not known.

The Department of Defense provides information on a program offering funds of up to \$350 per month for services to severely mentally retarded or physically impaired, including deaf-blind, dependents of servicemen. The program provides for diagnosis; in-patient, out-patient, and home treatment; training; rehabilitation; and special education. It also covers institutional care in public and private nonprofit institutions and transportation to and from these facilities.

The federal Health Services and Mental Health Administration provides information on health programs for American Indians and Alaskan natives and family health clinics for handicapped children of migratory workers.

Education Programs

Most of the resources for the education of handicapped children, other than those who are deaf-blind, are provided by state education agencies and local public schools. State agencies utilize both their own and federal funds, which they transfer to local districts or private schools for the operation of special education programs. Operation of residential schools for the visually and/or acoustically handicapped and mentally ill and retarded children is part of most state education programs. The states provide reading materials, special teachers, special classes, equipment and transportation to and from schools. Information on these programs is available from state consultants for the various disabilities in the departments of education of the states.

Because of the excessive costs required for the education of comparatively few numbers of deaf-blind children who are dispersed over a wide geographic area, it became necessary for the federal government to provide needed services through

regional planning and distribution of funds. In 1967 the federal government provided model centers for deaf-blind children in an effort to secure educational programs for them. Today services are provided in various types of public and private residential schools, in local public and private schools or centers, at homes and elsewhere, almost exclusively through funds provided by the federal government to the Regional Centers for Services to Deaf-Blind Children, to state departments of education, and to local programs. (See page 324 for a listing of the current regional centers.)

Any of the regional center coordinators will provide information on services offered in a region. Services generally cover the following: identification of deaf-blind children through diagnostic and evaluative services, consultative and training programs for parents and service personnel, and educational programs and services for deaf-blind children. The consultant for deaf-blind children in the state department of education of the region and the regional center education consultant can often facilitate access to service, individualizing and matching the services available to individual children's needs. These coordinators are also able to coordinate services of the regional center with those services offered by other agencies.

State coordinators for deaf-blind children prepare annual reports on the progress, needs, and goals for children within the state, and these reports may be requested for review. In cooperation with coordinators of other state programs for the handicapped, they provide needed workshops for inservice training of personnel.

The Regional Centers for Services to Deaf-Blind Children use a number of techniques to provide information to constituencies. Several will be mentioned here to represent the types offered and to suggest to readers the usefulness of the regional center information services.

Many, if not all, of the Regional Centers for Services to Deaf-Blind Children publish newsletters and brochures for parents and those who serve deaf-blind children in a region. For example, the Mid-Atlantic, North, and Caribbean Regional Center, in a five-page illustrated brochure, provides answers to a number of questions about the center and the services available throughout the region. The Midwest Regional Center publishes *Sights and Sounds*, a newsletter by and for the parents of deaf-blind children of the region, while the Southwest Regional Center, in collaboration with John Tracy Clinic, offers the John Tracy Clinic Corres-

pondence Course, a tailor-made program for parents of deaf-blind children, available in English and Spanish editions. Organized into several study units based upon various skills such as communications, gross motor, fine motor, self-dressing, toileting, and others, each unit is divided into lessons applicable to the needs and progress of the individual child. Compiled and updated annually by the Southwest Regional Center is yet another type of publication, the *Bibliography of Proceedings and Publications of Regional Deaf-Blind Centers*. This bibliography includes information on every publication of the ten regional centers and contains a section on "Media Development for Training Purposes," in which videotapes and other media prepared by the regional centers are documented. An example of a film included in this publication is *Children of the Silent Night*, a 27-minute, 16 mm color-sound motion picture showing how deaf-blind children are being educated at the Perkins School for the Blind.

The South Central Regional Center developed and distributed to all teachers of deaf-blind children in the region a loose-leafed teacher's resource notebook comprised of ideas for curriculum materials to use, a section on assessment scales, a bibliography, and a description of the role and services of regional consultants.

All of the regional deaf-blind centers sponsor and conduct workshops for families of deaf-blind children. The Southwest Regional Center, in cooperation with John Tracy Clinic, developed Project Spin Off to train home visitors in skills required to provide information and support to families in any region in which deaf-blind children currently are living at home and not receiving other services. The Midwest Regional Center, in cooperation with Michigan State University, offers annually an intensive summer workshop in methodology and practice with deaf-blind children the following school year. These and other regional centers conduct workshops for resource personnel. The workshops vary in duration from one day to several weeks. All of the regional centers have had some funds to offer some stipend support to candidates. Moreover, the Division of Personnel Preparation of the federal Bureau of Education for the Handicapped provides assistance for undergraduate and graduate training and summer school programs through colleges and universities with approved training programs.

A number of other federal programs, sponsored by the Bureau of Education for the Handicapped and other agencies, provide useful services to

benefit deaf-blind persons. These provide information on recreation, media and materials, education, and related services, including federal schools for the deaf, community and junior colleges which offer training for deaf persons, preparation of personnel for the education of deaf-blind children, and research. The programs are summarized in the pages that follow.

The National Institute on Program Development and Training in Recreation for Deaf-Blind Children, Youth and Adults offers information on leisure education and recreation for deaf-blind persons. The institute is located at the University of Iowa and provides model recreation programs and materials which can be used by recreation specialists and teachers to enrich the lives of deaf-blind persons of all ages. Their newsletter is available from the project coordinator.

The American Printing House for the Blind manufactures and distributes books and other materials for use by the visually impaired and deaf-blind. School-age children registered with them who are legally blind qualify for a specified annual quota of free educational materials, including media such as braille-writers, braille slates, writing paper, books in large type, books in braille, recorded books, and playback equipment for records and voice tapes. The consultant for the visually handicapped in each state department of education provides information on the eligibility and registration of children and on procedures for ordering materials and equipment.

Information on activities of the National Advisory Committee on Handicapped Children is provided by the Executive Secretary, Bureau of Education for the Handicapped. The committee's activities include the review of the administration and operation of federal programs for handicapped children and development of recommendations for the improvement of these programs.

The federal government, in collaboration with nine colleges and universities in the United States, offers financial support for the preprofessional training of teachers, resource consultants, coordinators, supervisors, administrators, researchers, and college teachers in the education of deaf-blind children and youth. A listing of these approved programs is provided on page 323. Program coordinators will provide information on admission procedures, requirements, fees, housing, and programs, as well as some guidance regarding career goals. In addition to regular programs, some of the colleges and universities offer special summer courses, inservice education, paraprofessional education,

bibliographies and printed materials, speakers on request, and personnel participation on advisory committees, at professional meetings, for identification and screening of children, and related activities.

Sources of federal and other funds for research in the various aspects of the education of deaf-blind children and related information is provided by the Division of Educational Research of the Bureau of Education for the Handicapped, United States Office of Education. Research grants are provided through several of the federal programs for both basic research and demonstration projects. State funds are sometimes available for those interested in experimenting in alternate methods of educating deaf-blind children.

Vocational Services

Federal and state vocational rehabilitation and employment programs for deaf-blind persons in the United States are provided by the federal Social and Rehabilitation Service Administration to prepare the deaf-blind for or return them to the world of work. The key for eligibility to services is that the deaf-blind or other handicapped person will be employable after receiving services. Work may be in the competitive labor market, sheltered employment, homebound work, or family work. Obviously, the least handicapped of those eligible for services represent the highest number of persons accepted for rehabilitation services and successfully placed in employment. Because of this, in 1969 the federal government established a National Center for Deaf-Blind Youths and Adults to stimulate the development of improved services for this group in state and local rehabilitation agencies. Operated by the Industrial Home for the Blind under contract with the federal government, the national center will soon move into its new \$75 million permanent facilities under construction at Sands Point, Long Island. The national center is intended to provide comprehensive service through residential facilities, consultative aid to other organizations, demonstration of methods of services, personnel training, and research on services to the deaf-blind. When operational, it will supplement services offered by state and local rehabilitation programs by providing in-depth rehabilitation services to 100 of the most difficult to rehabilitate deaf-blind clients annually. A 15-minute, 16mm sound film describing the program of the national center is available on a free-loan basis from the National Audio Visual Center, Washington, D.C.

The federal government today provides about 80 percent of the cost of basic vocational rehabilitation services to state programs, which in turn provide vocational training, counseling, prosthetics, placement, and other needed services to all types of physically and mentally handicapped persons with vocational potential, including those who are deaf-blind. The program also supports research related to rehabilitation and employability, the construction of physical plants, and the training of professional personnel.

Four state agencies provide information on programs designed to facilitate the employment of rehabilitated handicapped persons. They are:

1. The governor's committee on employment of the handicapped and corresponding local committees, which, like the President's committee, promote employment of mentally and physically handicapped persons.
2. The state civil service commissions, which provide federal employment of handicapped persons
3. The federal Randolph-Sheppard Vending State Programs, which provide employment for visually handicapped persons in government buildings.
4. The state employment services programs, which also facilitate employment of handicapped persons.

Each state has a variety of services for blind and deaf-blind clients, including such program components as home teaching of adults, including housewives; special programs for blind and deaf-blind children involving social work with the family to improve their understanding of the handicap(s); workshops; and payment of special medical expenses.

Mental Health and Mental Retardation

Facilities for the mentally handicapped and mentally ill persons are presumed to be serving deaf-blind persons, but because of uneven and almost nonexistent reporting practices, the exact number is not known. However, since programs for mentally ill and mentally retarded persons can and do serve some deaf-blind persons, resources for information about their services is pertinent to our interests here.

Federal, state, and local programs serving handicapped persons target almost half of their monies to meet the needs of those who are mentally handicapped. The federal share in such programs is less than 10 percent. Most children who are

mentally ill or mentally retarded are treated in out-patient facilities while adults are provided more in-patient residential care. The two largest programs are administered by the federal Social and Rehabilitation Service through its Developmental Disabilities Program serving retarded persons and the National Institute of Mental Health's Community Health Center program, designed for treatment of the mentally ill.

Other useful resources providing specific diagnostic and counseling services to mentally retarded children are the federal Maternal and Child Health and Crippled Children's Services, offered through approximately 150 mental retardation clinics in state and local offices of public health departments.

Financial Assistance

The federal, state, and local governments collaborate in a number of income assistance and social insurance programs, many of which are operated within the states and funded jointly by federal, state, and local governments. In 1970, for example, approximately one million needy physically or mentally handicapped persons under age twenty-two received about \$635 million, 55 percent of which was provided by the federal government, 35 percent by the states, and 10 percent by local governments. These programs are Social Security Disability Insurance, Aid to Families with Dependent Children, Supplementary Security Income, General Assistance, and Income Tax Exemptions for the Blind. All but the latter are administered by the Social Security Administration of federal, state, and local governments. Information on the latter is secured through federal, state, or local offices of the Internal Revenue Service.

All of the above programs are aimed at the needy rather than the handicapped. However, most of the financial assistance to handicapped persons is provided through the Aid to Families with Dependent Children program. Financial assistance to handicapped children is provided in this program only if they are members of needy families seeking and qualifying for aid. Allowance is not made for the added expense of a handicapped child in a family receiving aid, nor is the program one that searches for handicapped children. However, since the program serves more handicapped children than all others, it indeed provides a good base for screening and identifying handicapped children, providing medical and sensory aid service to them, and assisting in directing parents to other useful services such as counseling for parents and children and early childhood education programs.

The federal Old Age, Survivors, and Disability Insurance system covers American workers against loss of income from death, disability, or retirement. If a worker covered by the insurance becomes disabled or when he or she reaches retirement age, the worker and specified dependents are entitled to certain benefits. If a worker dies, certain surviving relatives are entitled to specified benefits. Children of insured workers, disabled or not, are eligible to receive benefits. Blind and deaf-blind workers are exempted from specific provisions required for eligibility for benefits. Handicapped children who are dependents of an insured, disabled, retired, or deceased worker may receive benefits under certain conditions of the Social Security Act Childhood Disability Beneficiary Program.

The federal Supplementary Security Income program, which is relatively new, provides a uniform payment level that may be supplemented by the states to eligible blind and disabled persons, regardless of age. The payment level of the program is significantly higher than average payments of the Aid to Families with Dependent Children program. The General Assistance program authorizes state and local governments to provide persons with financial assistance. Persons discovered to be handicapped are probably removed from these programs, however, and shifted to a financial support program for which federal funding is available. Not all states and local governments participate in this program.

In addition to the public programs described, many states offer additional welfare benefits such as medical services, food assistance, and special aid to blind, crippled, or severely impaired persons. State and local public health and welfare departments provide information on these programs.

Private Programs and Information Resources

Interspersed with the public services is the largely independent group of organizations and agencies supported almost entirely by private philanthropy, comprising the private sector of information resources. Compared to the number of blind, deaf, or deaf-blind persons it reaches and assists, it is enormous. One is surprised by the fact that almost every town and city has an organization or a service reaching the blind or the deaf through which the deaf-blind may be served. Moreover, these organizations provide unusual functions and raise large sums of money to carry on their missions through such agencies as the United Fund, Lions Clubs, local community chests,

and private philanthropic foundations. The *Directory of Agencies Serving Blind Persons in the United States* and the *American Annals of the Deaf Directory of Programs and Services* establish the parameters of the resources. Volunteers are used extensively to provide services that are primarily offered to young children and adults, with few services focused on the rehabilitation and care of the older people who comprise the largest group of the deaf-blind. Although the aged could benefit greatly from some of the programs, almost no effort is made to acquaint them with the services, the materials, or the techniques of communication and adjustment available to them. In the private sector, residential home care is the most significant service provided to the aged deaf-blind.

The amount of monies expended by the private sector for services is of great magnitude and importance to the quality of life of blind and deaf-blind persons. Information is provided about nursery schools, residences for the deaf-blind, braille libraries, braille instruction, summer camps for children and adults, low-vision services, social services, medical dispensaries, community programs for the aged, adolescent training, psychiatric services, rehabilitation services, sheltered workshops, recreation and day camping, volunteer reading, transportation, home skills training for housewives, home industrial arts, oral and manual communication, and mobility. While each agency and organization provides information about its own services, the United Fund office in a local community or the state office of the United Fund often can provide the needed information on all services available to deaf-blind persons in a community, state, or region. For example, in Michigan, the United Fund publishes a directory of United Fund agency services in the state and distributes it to corresponding community agencies.

The private agency that provides information to teachers, students, administrators, teacher educators, directors, researchers, and parents across the broad spectrum of special education is the Council for Exceptional Children. It is assisted by the public National Center on Educational Media and Materials for the Handicapped and is augmented by the American Printing House for the Blind and the American Foundation for the Blind. The Perkins School for the Blind, a private residential school for visually handicapped and deaf-blind children, publishes a number of instructional manuals dealing with curriculum, educational practices, and media for deaf-blind children. The Regional Centers for Services to Deaf-Blind Children are helpful

in locating materials and using information provided by the above agencies.

A large part of the educational and vocational rehabilitation research is reported by private agencies through such professional journals as *Exceptional Children*, *American Annals of the Deaf*, *Education of the Visually Handicapped*, *Journal of Rehabilitation*, *Journal of Special Education*, *New Outlook for the Blind*, *The Exceptional Parent*, *Focus on Exceptional Children*, *Rehabilitation Literature*, and *Rehabilitation Record*.

The American Foundation for the Blind and the American Printing House for the Blind provide pamphlets and bulletins containing practical information for parents of young deaf-blind children, bibliographies, and a host of other publications regarding the sources of reading materials, religious materials, aids, and appliances that they develop. Persons with ideas or prototypes of media or materials for deaf-blind persons may consult with staff members of these two agencies to assist them in improving the products.

While a number of parent groups have developed throughout the country, the Washington Association for Deaf-Blind Children is perhaps representative of the others. The association is composed of parents of deaf-blind children and other interested persons. It meets once each month in different locations throughout the state. Its members provide information to new families on available services in the state, deal with legislative questions, explore vocational services and educational programs, and investigate the possibility of establishing a home group and foster home placement for children needing this care.

Another service that is representative of other similar summer programs is the New York Institute for the Education of the Blind's annual summer residential camping program in Hardwick, Vermont, for visually handicapped and deaf-blind children. It is open to eligible deaf-blind children in the United States, and information on this and other camps is available from the camp directors or the coordinators of Regional Centers for Services to Deaf-Blind Children.

Other private programs that offer information on various types of direct services offered to deaf-blind children and adults include the Rubella Birth Defects Evaluation Project at Roosevelt Hospital, New York City, which provides diagnostic and evaluation services for deaf-blind children, and the Industrial Home for the Blind, which provides information on a preschool program operated for deaf-blind children, a sheltered work-

shop, and vocational training programs for deaf-blind youth and adults.

Information Resources

Since information on services is difficult for parents, professionals, researchers, and deaf-blind persons to acquire, lists of some of the information resources are provided here, with addresses. Included are known directories of agencies; professional organizations; conventions; programs preparing teachers for deaf-blind children; federal offices providing information on federal, state, and local programs and services to deaf-blind persons; Regional Centers for Services to Deaf-Blind Children; the federal network of media services for handicapped children; and periodicals.

Summary

The present stress on the optimal enrichment of the quality of life for all persons has generated more concern for those who are severely and multiply handicapped. This concern is manifested through the proliferation of information and service programs conducted and designed to help handicapped persons.

This chapter has attempted to present an array of information resources on service programs which in some way aid deaf-blind children and adults. A comprehensive information processing and dissemination system could perhaps eradicate duplication, misinformation, or lack of information, especially for deaf-blind persons, their families, and others genuinely concerned with improving the lives of deaf-blind persons.

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Annual Directories

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- Colleges and Universities Receiving Teaching and Traineeship Grants for the Preparation of Teachers of Deaf-Blind Children and Youth.* Washington, D.C.: U.S. Department of Health, Education, and Welfare, Bureau of Education for the Handicapped.
- Colleges and Universities Receiving Teaching and Traineeship Grants for Rehabilitation Counselor Training.* Washington, D.C.: U.S. Department of Health, Education, and Welfare, Social and Rehabilitation Services, Rehabilitation Services Administration.
- Directories of Agencies.* New York: National Association of Social Workers.
- Directory of Agencies Serving the Visually Handicapped in the United States.* New York: American Foundation for the Blind.
- Directory of Camps for the Handicapped.* Chicago: National Society for Crippled Children and Adults, and the American Camping Association.
- Directory of Catholic Special Facilities and Programs in the United States for Handicapped Children and Adults.* Washington, D.C.: National Catholic Education Association.
- Directory for Exceptional Children, Educational and Training Facilities.* Boston: Porter-Sargent.
- Directory, Jewish Federations, Welfare Funds, and Community Councils.* New York: Council of Jewish Federations and Welfare Funds.
- Directory of Legal Aid and Defender Services.* Chicago: National Legal Aid and Defender Association, American Bar Center.
- Directory of Nonprofit Homes for the Aged.* New York: American Association of Homes for the Aging.
- Directory of Programs and Services.* New York: American Annals of the Deaf.
- Directory of Rehabilitation Facilities.* Washington, D.C.: Association of Rehabilitation Centers, Inc.
- Directory of Regional Centers and Educational Programs Providing Services to Deaf-Blind Children and Youth in the U.S., Including Puerto Rico and the Virgin Islands.* Great Lakes Region SEIMC. East Lansing, Mich.: Michigan State University.
- Directory of Sheltered Workshops.* Washington, D.C.: National Institute on Workshop Standards.
- Directory for Special Education.* Fryeburg, Maine: American Association of Special Educators.
- Directory of Special Education Personnel in State Agencies.* Washington, D.C.: Department of Health, Education, and Welfare.
- Directory of State, Territorial, and Regional Health Authorities.* Washington, D.C.: Department of Health, Education, and Welfare, Public Health Service.
- Directory of State Societies for Crippled Children.* Chicago: National Society for Crippled Children and Adults.
- Directory, United Community Funds.* New York: United Community Funds and Councils of America, Inc.
- Directory of Workshops for the Handicapped.* Washington, D.C.: U.S. Department of Health, Education, and Welfare, Vocational Rehabilitation Administration.
- Easter Seal Directory of Resident Camps for Persons with Special Health Needs.* Chicago: National Easter Seal Society for Crippled Children and Adults.
- The Foundation Directory.* New York: The Foundation Library Center.
- Handbook on Programs of the U.S. Department of Health, Education, and Welfare.* Washington, D.C.: U.S. Department of Health, Education, and Welfare.
- Health Organizations of the United States, Canada, and International.* Ithaca, New York: Cornell University.
- Maternal and Child Health Service Programs.* Washington, D.C.: U.S. Department of Health, Education, and Welfare, Public Health Services.
- Public Welfare Directory.* Chicago: American Public Welfare Association.
- Sheltered Workshops and Homebound Programs—A Directory.* Washington, D.C.: National Association of Sheltered Workshops and Homebound Programs.

Directory of Resources

Federal Offices under the Jurisdiction of:
Department of Health, Education, and Welfare
330 Independence Ave., SW,
Washington, DC 20201

PUBLIC HEALTH SERVICES

Health Services and Mental Health Administration
5600 Fishers Lane
Rockville, MD 20852

National Institute of Mental Health
Community Mental Health Programs
Medicaid
Crippled Children's Services
Maternal and Child Health Services
Indian Health Services

National Institute of Health
9000 Rockville Pike
Bethesda, MD 20014

National Center for Disease Control
1600 Clifton Road, NE,
Atlanta, GA 30333

OFFICE OF EDUCATION

Bureau of Education for the Handicapped
400 Maryland Ave.
Washington, DC 20202

Director, Division of Educational Services
Coordinator, Deaf-Blind Regional Centers
Director, Division for Personnel Preparation
Director, Division for Educational Research
National Advisory Committee on Handicapped
Children
National Center on Educational Media and
Materials for the Handicapped/Regional
Resource Centers/Area Learning Resource
Centers/Special Offices (NCEMMH/RRC/ALRC/
SO) Network Coordinator

Closer Look
Box 1492
Washington, DC 20013

SOCIAL AND REHABILITATION SERVICES

Rehabilitation Services Administration
330 C St., SW
Washington, DC 20201

Developmental Disabilities Program
Director, Office for the Blind and Visually
Handicapped

National Center for Deaf-Blind Youth and Adults
Sands Point
Long Island, NY

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Social Security Administration
6401 Security Boulevard
Baltimore, Maryland 21235

SSDI—Social Security Disability Insurance
AFDC—Aid to Families with Dependent Children
SSI—Supplementary Security Income
GA—General Assistance

Other Resources at the Federal Level (Not under HEW)

DEPARTMENT OF THE TREASURY

Internal Revenue Service
Fifteenth St. and Pennsylvania Ave., NW
Washington, DC 20220

ITEB—Income Tax Exemptions for the Blind

LIBRARY OF CONGRESS

Division for the Blind and Physically Handicapped
1291 Tayler St., NW,
Washington, DC 20542

DEPARTMENT OF DEFENSE

The Pentagon
Washington, DC 20301

VETERANS ADMINISTRATION

Vermont Avenue between H and I Sts., NW
Washington, DC 20420

Department of Medicine and Surgery
Department of Veterans' Benefits
Education and Rehabilitation Services

SELECTED BOARDS, COMMITTEES, AND COMMISSIONS

President's Committee on Mental Retardation
Washington, DC 20201

Secretary's Committee on Mental Retardation
Department of Health, Education, and Welfare
Office of the Secretary
4513 North Building
330 Independence Ave.
Washington, DC 20201

President's Committee on Employment of the
Handicapped
U.S. Department of Labor
Washington, DC 20210

Federally Aided Corporations

Office of the President
Gallaudet College
7th St. and Florida Ave., NE
Washington, DC 20002

Director
Kendall School
Gallaudet College
7th St. and Florida Ave., NE
Washington, DC 20002

Other Resources

ACTION for Brain-Handicapped Children
4020 Minnetonka Blvd., No. 305
Minneapolis, MN 55416

American Foundation for the Blind
15 W. 16th St.
New York, NY 10011

Washington Office: Suite 213
1660 L St., NW
Washington, DC 20036

American Foundation for Overseas Blind
17 West 16th St.
New York, NY 10011

American Printing House for the Blind
1839 Frankfort Ave.
Louisville, KY 40206

Sex Information and Education Council of the
U.S.
1855 Broadway
New York, NY 10003

Goodwill Industries of America, Inc.
9200 Wisconsin Ave.
Washington, DC 20014

National Center for Law and the Handicapped
1235 N. Eddy St.
South Bend, IN 46617

National Society for the Prevention of Blindness,
Inc.
16 East 40th St.
New York, NY 10016

The Perkins School for the Blind
Watertown, MA 02172

Information Center—Recreation for the Handi-
capped
Outdoor Laboratory
Little Grassy
Southern Illinois University
Carbondale, IL 62901

Information Center for Hearing, Speech, and Dis-
orders of Human Communication
Johns Hopkins Medical Institution
Baltimore, MD 21205

Deafness Research Foundation
366 Madison Ave.
New York, NY 10017

Professional Organizations

Alexander Graham Bell Association for the Deaf,
Inc.
3417 Volta Place
Washington, DC 20007

Conference of Executives of American Schools for
the Deaf
5034 Wisconsin Ave., NW
Washington, DC 20016

Convention of American Instructors of the Deaf
5034 Wisconsin Ave., NW
Washington, DC 20016

National Catholic Educational Association
Special Education Section
1 DuPont Cir.
Washington, DC 20036

Council for Exceptional Children
Division for the Visually Handicapped: Blind and
Partially Seeing
1920 Association Dr.
Reston, VA 22091

American Association of Workers for the Blind,
Inc.
1511 K St., NW, Suite 637
Washington, DC 20005

American Association of Special Educators
P.O. Box 168
Fryeburg, ME 04037

American Association on Mental Deficiency
5201 Connecticut Ave., NW
Washington, DC 20015

Association for Education of the Visually Handi-
capped
919 Walnut St.
Philadelphia, PA 19107

American Rehabilitation Counseling Association of
American Personnel and Guidance Association
1607 New Hampshire Ave., NW
Washington, DC 20009

American Speech and Hearing Association
9030 Old Georgetown Rd.
Washington, DC 20014

Association for Children with Learning Disabilities
2200 Brownsville Rd.
Pittsburgh, PA 15210

Conference of Executives of American Schools for
the Deaf
c/o Howard M. Quigley
5034 Wisconsin Ave., NW
Washington, DC 20016

National Catholic Educational Association
Special Education Department
4472 Lindell Blvd.
St. Louis, MO 63108

The National Easter Seal Society for Crippled
Children and Adults
2023 West Ogden Ave.
Chicago, IL 60612

Council for Exceptional Children
1920 Association Dr.
Reston, VA 22091

Council of Organizations Serving the Deaf
Wilde Lake Village Green
Suite 310
Columbia, MD 21044

Council on Education of the Deaf
Colorado School for Deaf and Blind
33 N. Institute
Colorado Springs, CO 80903

Goodwill Industries of America, Inc.
9200 Wisconsin Ave.
Washington, DC 20014

International Society for Rehabilitation of the
Disabled
219 E. 44th St.
New York, NY 10017

International League of Societies for the Mentally
Handicapped
12, Rue Forestiere, 1050
Brussels, Belgium

National Association for Retarded Citizens
2701 Avenue E, East
Arlington, TX 7

National Association of the Deaf
814 Thayer Ave.
Silver Spring, MD 20910

National Rehabilitation Association
1522 K St., NW
Washington, DC 20005

ANNUAL AND BIENNIAL CONVENTIONS

Convention of American Instructors of the Deaf
International Congress on Education of the Deaf
International Association of Parents of the Deaf
Council for Exceptional Children
Association of Education of the Visually Handicapped
American Association of Workers for the Blind

PERIODICALS

American Annals of the Deaf
Exceptional Children
The Exceptional Parent
Focus on Exceptional Children
Journal of Rehabilitation

Journal of Special Education

New Outlook for the Blind
Rehabilitation Literature
Rehabilitation Record
The Lantern (Perkins School for the Blind, Watertown, Mass.)
The Volta Review
Touch-and-Go (for deaf-blind persons; American Foundation for the Blind)
Journal of Speech and Learning Research
The Deaf American
Education of the Visually Handicapped
Special Children
American Journal of Mental Deficiency
Mental Retardation

Colleges and Universities Preparing Personnel for the Education of Deaf-Blind Children and Youths

Madge Leslie
Department of Special Education
Portland State College
Portland, OR 97207

Sheldon Maron
Department of Special Education
Florida State University
Tallahassee, FL 32306

Verna Hart
Department of Special Education
University of Pittsburgh
Pittsburgh, PA 15213

William Myers
Department of Special Education
University of Texas
Austin, TX 78712

Lawrence Campbell
Department of Special Education
California State University, Los Angeles
Los Angeles, CA 90032

Barbara Franklin
Department of Special Education
California State University, San Francisco
San Francisco, CA 94132

Rebecca DuBose
Multihandicapped Project Director
George Peabody College for Teachers
Nashville, TN 37203

Graduate School of Arts and Sciences
Department of Special Education
Boston College
Chestnut Hill, MA 02167

Lou Alonso, Coordinator
Programs Preparing Personnel for the Visually
Handicapped and Blind/Deaf
Michigan State University
East Lansing, MI 48823

Regional Centers Serving Deaf-Blind Children

Center	States comprising regions	
Southwestern California State Department of Education 721 Capitol Mall Sacramento, CA 95814	Arizona California Hawaii American Samoa	Nevada Guam Trust Territories Navajo Nation
South-Atlantic 327 Hillsboro St. Bunn-Hatch Building Raleigh, NC 27611 (919) 733-3619	District of Columbia Maryland North Carolina	South Carolina Virginia West Virginia
Southeastern Alabama Institute for the Deaf and the Blind Box 698 Talladega, AL 35160 (205) 362-8460	Alabama Florida Georgia	Kentucky Mississippi Tennessee
Mid-Atlantic and Caribbean New York Institute for Education of the Blind 999 Pelham Parkway Bronx, NY 10469 (212) 547-1234	Delaware New Jersey New York	Pennsylvania Puerto Rico Virgin Islands
South Central Callier Campus 1966 Inwood Road Dallas, TX 75235 (214) 634-8003	Arkansas Louisiana Missouri	Oklahoma Iowa
Midwest P. O. Box 420 Lansing, MI 48902 (517) 373-0108	Illinois Indiana Michigan	Ohio Wisconsin Minnesota
Mountain Plains 165 Cook St., Suite 304 Denver, CO 80206 (303) 399-3070	Colorado Kansas Nebraska North Dakota	New Mexico Utah Wyoming South Dakota
Texas Education Agency Special Education Program for the Deaf-Blind 201 E. Eleventh Austin, TX 78701 (512) 475-3507	Texas	
Northwest 3411 South Alaska Street Seattle, WA 98118 (206) 464-6694	Alaska Idaho Montana	Oregon Washington
New England Perkins School for the Blind 175 North Beacon Street Watertown, MA 02172 (617) 924-3434	Connecticut Maine Massachusetts	New Hampshire Rhode Island Vermont

Bureau of Education for the Handicapped

Federal Network of Media Services

The National Center on Educational Media
and Materials for the Handicapped
The Ohio State University
220 West 12th Ave.
Columbus, OH 43210



Coordinating Office for the Regional Resource Centers
Bradley Hall, Room 114
University of Kentucky
Lexington, KY 40506



Special Office for the Visually Impaired
American Printing House for the Blind
Box 6085
Louisville, KY 40206

Specialized Office for the Handicapped
Wisconsin Research and Development Center for
Cognitive Learning
1025 West Johnson Street
Madison, WI 53706

Specialized Office for the Deaf and Hard of Hearing
University of Nebraska
175 Nebraska Hall
Lincoln, NE 68508

Specialized Office for Materials Distribution
Audio-Visual Center
Indiana University
Bloomington, IN 47401

Resource Centers Network

Regional resource centers	States served	Area learning resource centers
Northwest Regional Resource Center University of Oregon Clinical Services Building 3rd Floor Eugene, OR 97403	Alaska, Hawaii, Samoa, Guam, Trust Territory, Washington, Oregon, Idaho, Montana, Wyoming	Northwest Area Learning Resource Center University of Oregon Clinical Services Building, 3rd Floor Eugene, OR 97403
California Regional Resource Center 600 South Commonwealth St. Suite 1304 Los Angeles, CA 90005	California	California Area Learning Resource Center 600 South Commonwealth St. Suite 1304 Los Angeles, CA 90005
Southwest Regional Resource Center 2363 Foot Hill Dr., Suite G Salt Lake City, UT 84109	Nevada, Utah, Colorado, Arizona, New Mexico Bureau of Indian Affairs schools	Southwest Area Learning Resource Center New Mexico State University Las Cruces, NM 88003
Midwest Regional Resource Center Drake University 1332 26th St. Des Moines, IO 50311	North Dakota, South Dakota, Nebraska, Kansas, Oklahoma, Iowa, Missouri, Arkansas	Midwest Area Learning Resource Center Drake University 1336 26th St. Des Moines, IO 50311
Texas Regional Resource Center Texas Education Agency 211 East 7th St. Austin, TX 78701	Texas	Texas Area Learning Resource Center 2613 Wichita St. Austin, TX 78712
Great Lakes Regional Resource Center Wisconsin State Department of Public Instruction 126 Langdon St. Madison, WI 53702	Minnesota, Wisconsin, Michigan, Indiana	Great Lakes Area Learning Resource Center Michigan Department of Education P.O. Box 420 Lansing, MI 48902
Illinois Regional Resource Center Peoria Public School District 3202 North Wisconsin Ave. Peoria, IL 61603	Illinois	Illinois Area Learning Resource Center 1020 South Spring St. Springfield, IL 62706

Resource centers network (continued)

Regional resource centers	States served	Area learning resource centers
Ohio Regional Resource Center Ohio State Department of Education Division of Special Education 933 High St. Worthington, OH 43085	Ohio	Ohio Learning Resource Center Ohio State Department of Education Division of Special Education 933 High St. Worthington, OH 43085
Northeast Regional Resource Center 384 Stockton St. Hightstown, NJ 08520	Maine, Vermont, Massachusetts, New Hampshire, Rhode Island, Connecticut, New Jersey	Northeast Area Learning Resource Center 384 Stockton St. Hightstown, NJ 08520
New York Regional Resource Center City University of New York 144 West 125th St. New York, NY 10027	New York	New York Area Learning Resource Center New York State Education Department Division for Handicapped Children 55 Elk St., Room 117 Albany, NY 12234
Southeast Regional Resource Center Auburn University at Mont- gomery Montgomery, AL 36109	Louisiana, Mississippi, Alabama, Georgia, South Carolina, Flor- ida, Puerto Rico, Virgin Islands	Southeast Learning Resource Center Auburn University at Montgomery Montgomery, AL 36109
National Learning Resource Center of Pennsylvania 443 South Gulph Road King of Prussia, PA 19406	Pennsylvania	Pennsylvania Area Learning Resource Center 443 South Gulph Road King of Prussia, PA 19406
Mideast Regional Resource Center 1901 Pennsylvania Ave., N.W. Suite 505 Washington, DC 20006	Delaware, Mary- land, Virginia, West Virginia, Kentucky, Tennessee, North Carolina, Washington, D.C.	Mideast Area Learning Resource Center University of Kentucky Porter Building, Room 123 Lexington, KY 40506

Table 1
Public Health Programs for Deaf-Blind Persons

Agency	Type of services provided
Public Health Service (FEDERAL)	Identifies health hazards, delivers services, conducts research
Health Services/Mental Health Administration (FEDERAL)	Maintains regional offices to respond to state and local needs
Medicaid Programs (FEDERAL, STATE, and LOCAL)	Provides medical services for financially needy minors
Crippled Children's Services (FEDERAL, STATE, and LOCAL)	Provides medical services for financially needy minors with handicaps; genetic counseling
Maternal and Child Health Services (FEDERAL, STATE, and LOCAL)	Provides grant programs for vision and hearing screenings; dental care; well-child clinics; public health nursing visits to mothers and children; registration of handicapped children; genetic counseling
Center for Disease Control (FEDERAL, STATE, and LOCAL)	Provides for disease prevention; communicable disease control; immunization of children; rubella immunization; venereal disease prevention
Community Health Service (FEDERAL, STATE, and LOCAL)	Provides comprehensive health care services; health care for the children of migratory workers; rubella immunization; disease prevention
Indian Health Service (FEDERAL)	Provides hospitals, health care centers, school health centers; preventative and rehabilitative health services
National Institutes of Health (FEDERAL)	Conduct research and training in their own laboratories; offer contracts, grants, awards and fellowships; collaborate with other institutions and organizations
National Eye Institute (FEDERAL)	Develops Model Reporting Areas for Blindness statistics; research in prevention and treatment of eye diseases; vision research and training
National Institute for Neurological Diseases and Stroke (FEDERAL)	Provides for prevention research; prosthesis for the blind and aurally handicapped
National Institute for Dental Research (FEDERAL)	Conducts prevention research, including that for cleft lip and palate
National Institute of Allergy and Infectious Diseases (FEDERAL)	Conducts research into control of allergic, immunological, and infectious diseases related to sensory handicaps
National Institute of General Medical Sciences (FEDERAL)	Conducts genetic research for prevention of aural and visual handicaps

Table 1 (Continued) Public Health Programs for Deaf-Blind Persons

Agency	Type of services provided
National Institute for Child Health and Human Development (FEDERAL)	Conducts research directed to mentally retarded children
Veterans Administration, Department of Veterans' Benefits, Education and Rehabilitation Service (FEDERAL and STATE)	Maintains regional offices, hospitals, centers, domiciliaries, and outpatient clinics; educational assistance and special restorative training for wives and children of veterans who are permanently disabled, dead, prisoners of war, or missing in action
Department of Medicine and Surgery (FEDERAL)	Provides hospital, domiciliary, nursing home care, and outpatient medical services to veterans
Department of Defense (FEDERAL)	Provides inpatient, outpatient, and home treatment, training, rehabilitation, special education, and institutional care, including transportation to and from facilities, for mentally retarded or physically impaired dependents of servicemen

Table 2
Educational Resources for Deaf-Blind Persons (Federal Level)

Agency	Type of services provided
Division of Education Services	Coordinates and consults with ten Regional Centers for Services to Deaf-Blind Children
Division of Personnel Preparation	Provides information on educational programs preparing personnel; information on junior/community colleges offering training to deaf persons; fiscal support to a number of the above programs; information on National Institute on Programs Development and Training in Recreation for Deaf-Blind Children, Youth, and Adults
Closer Look	Assists parents in finding information on educational and related services; linkage with local organizations and agencies that may be able to help parents
National Center on Educational Media and Materials for the Handicapped (NCEMMH) Media and Captioned Films Branch Thirteen regional resource centers Thirteen area learning resource centers Four special offices	Media development; computer-based retrieval system for educational materials for handicapped
American Printing House for the Blind	Distributes braille books, recorded materials, and educational aids without cost to institutions educating blind children
National Training Institute for the Deaf	Provides technical and vocational training; B A and M A degree programs for deaf students; information on community and junior colleges throughout the country providing training programs for deaf persons
Gallaudet College Model Secondary School for the Deaf	Provides education in the liberal arts (graduate and undergraduate) for deaf persons needing special facilities; research program focusing on programs related to deafness; preschool for young deaf children; educational facility for deaf high school students operated by Gallaudet College
Kendall School for the Deaf	This is a demonstration school for the deaf located on the Gallaudet College campus.
Library of Congress Division for the Blind and Physically Handicapped (only agency included that is also at state level)	Includes main library plus 34 branch libraries providing information on braille books, records, and tapes for blind and physically handicapped persons; free circulation of books and equipment

Table 3
Vocational Services for Deaf-Blind Persons (Federal Level)

Agency	Type of services provided
Social and Rehabilitation Services Administration Office for the Blind and Visually Handicapped (also available at state and local levels)	Provides vocational training, counseling, prosthetics, placement, and other needed services to physically and mentally handicapped with vocational potential; support for research on rehabilitation and employability; construction of physical plants; training of professional personnel; home teaching of adults; social work to families; workshops; payment of special medical expenses
National Center for Deaf-Blind Youths and Adults	Provides comprehensive service through residential facilities; consultative aid to other organizations; demonstrations of methods of service; personnel training; research on services to deaf-blind persons; services to 100 of the most difficult to rehabilitate clients annually; circulates a free 15-minute 16mm film describing program, available from: National Audio Visual Center, Washington, DC, 20409; regional offices in Chicago, Atlanta, Dallas, Philadelphia, Glendale (California)

Table 4
Information Resources for Deaf-Blind Persons: Mental Health and Retardation

Agency	Type of services provided
Social and Rehabilitation Service (FEDERAL) Rehabilitation Services Administration (FEDERAL) Developmental Disabilities (FEDERAL, STATE, and LOCAL)	Provides grants to states for planning, services, and construction of facilities for persons with developmental disabilities; improvement of services in state-operated mental retardation facilities; construction and operation of university-affiliated facilities; increased services to the severely disabled
National Institute of Mental Health (FEDERAL, STATE, and LOCAL)	Maintains community mental health centers; mental health research on children; training grants to meet manpower needs; hospital improvement grants; operates St. Elizabeth's Hospital
Maternal and Child Health Services (FEDERAL, STATE, and LOCAL)	Provides diagnostic and counseling services to mentally retarded children
Crippled Children's Service (FEDERAL, STATE, and LOCAL)	Provides diagnostic and counseling services to mentally retarded children through about 150 mental retardation clinics throughout the country
National Institute for Child Health and Human Development (FEDERAL)	Conducts research mainly on retarded children; some research in perinatal biology and reproduction aimed in preventing sensory and other handicaps
President's and Secretary's Committees on Mental Retardation (FEDERAL)	Advises the President and Secretary on what is being done for the mentally retarded; promotes coordination and cooperation among public and private agencies; stimulates action and promotes understanding

Table 5
Financial Assistance for Deaf-Blind Persons

Agency	Type of services provided
Social Security Disability Insurance (SSDI) (FEDERAL, STATE, and LOCAL)	Maintains Old Age, Survivors, and Disability Insurance (OASDI) for American workers against loss of income from death, disability, or retirement; benefits for dependents, survivors, and handicapped children; reimbursements to vocational rehabilitation agencies for services rendered to clients
Aid to Families with Dependent Children (AFDC) (STATE and LOCAL)	Makes payments to needy families of handicapped children; screening and identification; medical and sensory-aid services; parent counseling; early childhood programs
Supplemental Security Income (SSI) (FEDERAL, STATE, and LOCAL)	Makes payment to eligible blind, disabled, and aged persons; reimburses vocational rehabilitation agencies for services
General Assistance (GA) (STATE and LOCAL)	Administers financial assistance program in coordination with state and local government
Internal Revenue Service Income Tax Exemptions for the Blind (ITEB) (FEDERAL, STATE, and LOCAL)	Allows exemptions for legally blind taxpayers or taxpayer's legally blind spouse

Table 6
Information Resources of Use to Deaf-Blind Persons

Agency	Type of serviced provided
Information services	
Council for Exceptional Children Information Center on Handicapped and Gifted Children (PRIVATE)	Makes custom computer searches to meet specific information needs; comprehensive print resources on a specific topic of concern, special interest papers, resource manuals, and topical bibliographies (Toll free telephone number is 800-336-3728.)
National Center on Media and Materials for the Handicapped (FEDERAL)	Makes custom computer searches on educational materials, curriculum, methods of teaching, and related topics
Information Center for Hearing, Speech, and Disorders of Human Communication of the Johns Hopkins Medical Institution (PRIVATE)	Makes custom data searches for professional personnel needing information on hearing, speech, and communication disorders
Sex Information and Education Council of the United States (PRIVATE)	Provides information on human sexuality, including information for handicapped individuals; publication of a quarterly newsletter, discussion guides, a library of reprints, and aids for use in initiating and developing a sex education program; provides consultation to school systems and teacher training institutions
American Printing House for the Blind (PRIVATE)	Provides information on the location of one-of-a-kind volunteer-produced materials which may be borrowed; books and materials for loan or purchase; information on local volunteer tape recording and braille services
Library of Congress, Division for the Blind and Physically Handicapped (FEDERAL)	Provides information on local volunteer tape recording and braille services; loan books on braille, large type, and recorded form
ACTION for Brain Handicapped Children (PRIVATE)	Maintains clearinghouse for information about brain handicap, actively communicating up-to-date advances and research to public, medical, and educational professions; monthly information bulletin, <i>Expectations</i> ; seminars and workshops
American Alliance for Health, Physical Education, and Recreation (PRIVATE)	Provides information for personnel developing or conducting school and community programs in health education, physical education, and recreation; publication of <i>Journal of Health, Physical Education, and Recreation</i> with a column on handicapped; <i>Research Quarterly</i> ; and <i>Update</i> .
Information Center—Recreation for the Handicapped, Outdoor Laboratory (PRIVATE)	Collects and disseminates information pertaining to recreation for all handicapped persons; publication of <i>ICRH Newsletter</i> ; <i>Recreation for the Handicapped</i> ; and a bibliography

Table 6 (Continued) Information Resources of Use to Deaf-Blind Persons

Agency	Types of services provided
Information services (Continued)	
International Association of Rehabilitation Facilities (PRIVATE)	Provides information on facilities for the handicapped
International League of Societies for the Mentally Handicapped (PRIVATE)	Provides information on facilities for mentally handicapped throughout the world; newsletter
American Foundation for the Blind (PRIVATE)	Maintains the National Committee for Deaf-Blind Children
American Foundation for Overseas Blind (PRIVATE)	Provides comprehensive information on international aspects of history, current education, and rehabilitation programs and practices with deaf-blind children and adults; maintains regional offices in several countries in the world; sponsors workshops and provides consultation to personnel of other countries on education and rehabilitation of the deaf-blind
Library services	
American Foundation for the Blind (PRIVATE)	Maintains the M. C. Migel Memorial Library on education and social care of the visually handicapped and the deaf-blind in the United States; many references out of print
Perkins School for the Blind (PRIVATE)	Maintains the Blindiana Library on education, history, and social care of the visually handicapped and deaf-blind
Library of Congress, Division for the Blind and Physically Handicapped (FEDERAL)	Maintains regional libraries throughout the United States, loaning books in braille, large type, and in recorded form, together with record players and tape playback equipment; free to eligible borrowers
Legal Information	
American Foundation for the Blind (PRIVATE)	Publishes bimonthly legislative newsletter, <i>Washington Report</i> ; lobbies, monitors, and reports Congressional activity and legislation affecting the blind and deaf-blind of all ages
National Center for Law and the Handicapped (FEDERAL)	Provides information on legislation and judicial decisions that affect the handicapped
Council for Exceptional Children Information Clearinghouse for Exceptional Children (PRIVATE)	Provides information about past and current federal and state legislative activities affecting handicapped persons

Table 6 (Continued) Information Resources of Use to Deaf-Blind Persons

Agency	Types of services provided
Legal information (Continued)	
Department of Health, Education, and Welfare, Bureau of Education for the Handicapped Associate Commissioner, Bureau of Education for the Handicapped	Provides information on past and current legal and legislative activities
Professional organizations standards for professional training	
Council for Exceptional Children (PRIVATE)	Publishes standards for professional training of teachers of handicapped children; publishes <i>Exceptional Children</i>; <i>Teaching Exceptional Children</i>; and many other publications
Association for the Education of the Visually Handicapped (PRIVATE)	Professional organization for teachers, administrators, and parents of the visually handicapped and deaf-blind; publishes <i>Education of the Visually Handicapped</i> and other publications; has biannual convention
National Accreditation Council for Agencies Serving the Blind (PRIVATE)	Reviews agencies offering services to the blind and deaf-blind; assists them in meeting the standards of accreditation
North American Committee on Services to Deaf-Blind Children and Youth (PRIVATE)	Sets standards for the education of deaf-blind children
National Catholic Education Association (PRIVATE)	Provides special education section for teachers of handicapped children in parochial schools
American Association of Workers for the Blind (PRIVATE)	Professional organization of personnel working with adult blind and deaf-blind persons
Prevention	
National Society for the Prevention of Blindness, Inc. (PRIVATE)	Professional and public education on prevention of blindness and conservation of vision; publishes newsletters, brochures, posters, and the journal, <i>Sight-Saving Review</i>; disseminates information on preventative research; has annual convention
Deafness Research Foundation (PRIVATE)	National voluntary health organization; conducts otological research; public information programs; Centurion Club of the Foundation, comprised of ear, nose, and throat medical specialists, raises funds for research and other foundation objectives
Research to Prevent Blindness (PRIVATE)	Contributes money to eye research and for laboratory facilities.

Table 6 (Continued) Information Resources of Use to Deaf-Blind Persons

Agency	Types of services provided
Media for education and rehabilitation	
American Foundation for the Blind (PRIVATE)	Produces and sells at cost aids, appliances, equipment, and other instructional media used in education and rehabilitation of deaf-blind persons; reports research findings in education and rehabilitation of deaf-blind persons; distributes films for public information and professional preparation
American Printing House for the Blind (PRIVATE)	Conducts research on educational materials, practices, and curriculum in education of visually handicapped and deaf-blind; manufactures aids, appliances, and media for education and rehabilitation; publishes standardized tests, braille, large type, and recorded materials; professional-use materials in education and rehabilitation, including materials for parents
Regional Centers for Services to Deaf-Blind Children (FEDERAL)	Provides print and media information on curriculum and educational practices; instructional films for professional in-service education; informational newsletters and annual reports
Council for Exceptional Children (PRIVATE)	Publishes catalogs of films on handicapped children
National Center for Deaf-Blind Youth and Adults (FEDERAL)	Provides information on media and rehabilitation practices; circulates a film describing the program
Consultation	
Coordinator, Regional Centers for Services to Deaf-Blind Children, Bureau of Education for the Handicapped (FEDERAL)	Consults with other agency personnel on programs or needs of deaf-blind children
Coordinators of the 10 Regional Centers for Services to Deaf-Blind Children (FEDERAL)	Consults with state department specialists and others in the establishment and conduct of programs for deaf-blind children in designated regions
Director of the Office for the Blind and Visually Handicapped, Rehabilitation Services Administration (FEDERAL)	Consults with agency personnel on rehabilitation and employment needs and programs for deaf-blind persons
Director, National Center for Deaf-Blind Youth and Adults (FEDERAL)	Consults with rehabilitation and employment agency personnel on rehabilitation needs, programs, and employment of deaf-blind persons.
Coordinators, Regional Offices of the National Center for Deaf-Blind Youth and Adults (FEDERAL)	Maintains offices in Glendale, California; Atlanta, Georgia; Chicago, Illinois; Philadelphia, Pennsylvania; and Dallas, Texas, to provide consultation on the rehabilitation of specific deaf-blind individuals

Table 6 (Concluded) Information Resources of Use to Deaf-Blind Persons

Agency	Types of services provided
Consultation (Continued)	
Education Consultant, American Foundation for the Blind (PRIVATE)	Consults with agencies, parents, and professionals on the education of deaf-blind children
Coordinators, Teacher Education Programs of the United States (PRIVATE and STATE)	Consults with teachers and parents regarding the education of deaf-blind children
State Consultants for the Education of the Deaf-Blind, State Department of Education (STATE)	Consults with teachers and parents on the education of deaf-blind children
Director, Personnel Preparation Programs, Bureau of Education of the Handicapped (PRIVATE)	Consults in teacher education in the area of the deaf-blind and in the education of deaf-blind children.